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# **SIGNS** *of* **SOLIDARITY**

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**Ministries with People Who  
Are Deaf, Late-Deafened,  
Hard of Hearing, and  
Deaf-Blind**

**Nancy Kingsley, Editor  
Rev. Kathy Black, Ph.D.  
Candis Shannon  
Rev. Kirk VanGilder  
Rev. Robert Walker, D. Min.**

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**The National Committee on Ministries with Deaf,  
Late-Deafened, Hard of Hearing, and Deaf-Blind People**

Second Edition

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**Signs of Solidarity:**

**Ministries with People Who Are Deaf, Late-Deafened, Hard of Hearing, or Deaf-Blind**

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## Preface to the Second Edition

**I**n 1992, the General Conference of The United Methodist Church established the National Committee on Deaf Ministries as a mission initiative (renewed at the 1996 and 2000 General Conferences). As its mission expanded to include all people with hearing loss, the committee broadened its name to reflect the diversity of the population it represents, and it is now known as the National Committee on Ministries with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People (National Committee for short).

One of the projects of the National Committee has been to update this manual. Written by the Reverend Kathy Black, Ph.D. in 1994, *Signs of Solidarity* has provided valuable information to churches on how to build a successful deaf ministry. New knowledge and resource materials needed to be incorporated into the manual, and Rev. Black graciously gave her permission and blessings to the National Committee to handle this revision work.

The Introduction, Part One: Deaf Ministry, and Part Two: Ministry with Late-Deafened and Hard of Hearing People have been completely revised and updated. Candis Shannon revised the Introduction, with contributions from Nancy Kingsley; Part One was updated by the Reverend Kirk VanGilder, with additional information from Vae Rose Fultz, Nancy Kingsley, and Candis Shannon; and Nancy Kingsley revised Part Two, with input from Candis Shannon and Rev. Dr. Robert Walker. A

new Part Three: In Solidarity with Deaf-Blind People was written by the Reverend Dr. Robert Walker, with contributions from Nancy Kingsley. Candis Shannon added "Ephphatha! Be Opened," a segment that touches on theological issues. Also new is a comprehensive Accessibility Audit for Ministry designed as a pullout section. This Audit is a major timesaver designed to aid various church communities in accessibility issues. The Resources section has been updated with many valuable books and videotapes that can help in building a strong inclusive ministry. Nancy Kingsley edited the entire revised edition of *Signs of Solidarity*.

Sincere thanks are extended to the members of the National Committee, the staff of the General Board of Global Ministries' Health and Welfare Ministries Unit (which oversees the United Methodist Congress of the Deaf), and to the UMCD members. Special thanks are extended to Holly Elliott and Laurel Glass, M.D., Ph.D., Past Presidents of the UMCD, and to Ginny Clark-Wright, Holly Elliott, Jill Grimshaw, "Mary Jones," Randi O'Donnell, and the Reverend Dr. Bob Walker for sharing their stories, prayers, and wisdom. Noemi Fuentes of the Health and Welfare Ministries Unit and National Committee Coordinator Rev. Dr. Peggy Johnson also deserve thanks for their support for this project. And thanks to Rev. Black for laying such a fine foundation in the original edition of this manual upon which to build.

**Signs of Solidarity Revision  
Subcommittee**

Candis Shannon, Chair  
Vae Rose Fultz  
Nancy Kingsley  
Rev. Kirk VanGilder  
Rev. Robert Walker, D.Min.

**The 2001-2004 National Committee  
on Ministries with Deaf, Late-  
Deafened, Hard of Hearing, and  
Deaf-Blind People**

Rev. Thomas Hudspeth, D. Min., President  
Candis Shannon, Vice-President  
Rev. Wineva Hankamer, Secretary  
Vae Rose Fultz

Jill Grimshaw  
Rev. Joo Hai Kang  
LeSander Saunders  
Rev. Kirk VanGilder  
Rev. Robert Walker, D.Min.  
Rev. Tizzy Von Trapp Walker

**Ex Officio**

Noemi Fuentes, General Board of Global  
Ministries Staff Representative  
Rev. Richard Gentzler, Jr., D.Min., General  
Board of Discipleship Staff Representative  
Rev. Peggy Johnson, D.Min., Consultant and  
Coordinator for the National Committee  
Georgia Lister, Director, 2000-2004, General  
Board of Global Ministries

## Preface to the Original (1994) Edition

*They brought to [Jesus] a deaf man who had an impediment in his speech; and they begged him to lay his hand on him. He took him aside in private, away from the crowd, and put his fingers into his ears, and he spat and touched his tongue. Then looking up to heaven, he sighed and said to him, "Ephphatha," that is, "Be opened." And immediately his ears were opened, his tongue was released, and he spoke plainly.*

Mark 7:32-35

Unless there is a miracle worker in your church, Jesus' way of empowering a deaf man to participate in a hearing world is not one of your options. Rather, it is for your church to "be opened" so that deaf, deafened, and hard of hearing persons can become full participants in the life of worship and Christian service centered there.

This resource is designed for hearing churches that are interested in becoming more

accessible to persons who are deaf, deafened, hard of hearing and deaf-blind. It deals with access to communication—attitudinally, functionally, and technologically—not only during worship services but also during planning sessions, committee meetings, educational programs, and social events. Numerous models of United Methodist deaf ministries will be described in case your church would like to emulate them.

The purpose of this resource is not to encourage ministries to or ministries for persons with hearing loss but to underline the need for churches to be in solidarity with persons who are deaf, deafened, hard of hearing and deaf-blind. The first step toward being opened is to recognize that these persons are eager to serve and can bring a valuable contribution to the life of the church. Their knowledge, experience, and enthusiasm form a source of energy waiting to be tapped, and this booklet will show you how to begin.

# Introduction

**T**he United Methodist Congress of the Deaf (UMCD) came into being in grassroots fashion as *culturally deaf*<sup>1</sup> members of various Methodist churches met with ministers and others interested in creating a national network for deaf ministry. (Culturally deaf people, designated by a capital "D," have their own language, sign language, and a culture based on this language and on their primary source of receiving information, which is through their eyes.) The first formal UMCD Congress was held in Tulsa, Oklahoma, in 1978.

At the 1992 United Methodist General Conference, Holly Elliott, a late-deafened General Council on Ministries representative from the California-Nevada Conference, gave a stirring address about inclusion based on Matthew 25:31-46. Her speech, a culmination of several consultations between the UMCD and the General Council on Ministries, served as an introduction to legislation that established the National Committee on Deaf Ministries. The National Committee recommended strategies for developing ministries with those who are Deaf, late-deafened, hard of hearing, or deaf-blind. Renamed the National Committee on Ministries with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People, it has focused on increasing awareness and access for these populations within the United Methodist Church.

Each group has different needs and viewpoints. For example, culturally deaf people see deafness not as a disability but as a way of life. On the other hand, *oral deaf* people (who, like most culturally deaf people, are born deaf or

lose their hearing *prelingually*—before acquiring spoken language) learn and use speech and *speechreading* to belong to the hearing world. Late-deafened people usually grieve the loss of their hearing and the activities that depended on hearing ability. Hard of hearing people tend to consider their hearing loss potentially disabling, and they work to remain a full part of the hearing world rather than learning sign language. Deaf-blind people have difficulty both hearing and seeing, and they use various coping skills depending on their background and their age of developing hearing loss. UMCD welcomes everyone regardless of their hearing or non-hearing status, works with individuals and local churches, and advocates to The United Methodist Church as a whole to "open the ears" of the Church.

## **DEAF, LATE-DEAFENED, HARD OF HEARING, AND DEAF-BLIND POPULATIONS**

The tendency is to classify all people with hearing loss as *hearing impaired*. This term is not appreciated by the culturally deaf, who belong to the *Deaf community* and communicate in *American Sign Language* (ASL) here in the U.S. and is increasingly avoided by those who are hard of hearing, late-deafened, or deaf-blind. Some people object to the implication of the word "impaired," which suggests they are defective, while others support the term as an accurate portrayal of their audiological state. "Hearing-impaired" is a generalization that

<sup>1</sup> Terms that are defined in the Glossary on page 83 are italicized on their first appearance in the Introduction and in each Part.

obscures the different realities and needs of those who are Deaf, late-deafened, hard of hearing, or deaf-blind. These differences are important and will greatly impact the kind of ministry a church chooses to engage in with its particular constituency.

Below is a basic summary of the different populations (it should be kept in mind that not everyone fits neatly into each of these categories). The statistical information comes from the National Institute on Deafness and Other Communication Disorders (NIDCD) and Self Help for Hard of Hearing People (SHHH).

- There are 28 million people with hearing loss in the US.
- Half a million people were born deaf (unable to understand speech through the ear) or became deaf before acquiring spoken language; most members of this group belong to the Deaf community, communicate in American Sign Language, and consider deafness a culture, not a disability.
- Ministries and social services for the Deaf community in America are based on American Sign Language and Deaf culture.
- One-and-a-half million people are late-deafened and lost the ability to understand speech through the ear after they acquired spoken language and were raised in the hearing community.
- Late-deafened people may or may not sign and usually require another form of visual input such as real-time captioning or computer-assisted notetaking.
- Twenty-six million people are hard of hearing. Although some were born hard of hearing or developed a hearing loss during childhood, most became hard of hearing later in life.
- Hearing loss becomes more common with

age and affects a third of senior citizens, but 60 percent of hard of hearing people are under 65.

- Hard of hearing people can understand speech with the help of hearing aids and *assistive listening systems*, but they are often ashamed of their hearing loss and unaware of the assistive equipment that can benefit them. Few know sign language. Assistive listening systems transmit and receive sound from a microphone directly to the hard of hearing listener, minimizing the negative effects of distance, background noise, and reverberation (echo) on clarity.
- Most, but not all, late-deafened and hard of hearing people belong to the hearing community and want to remain connected with it. They need technological and psychological assistance in coping with hearing loss and accepting the help they need.
- Ministries and social services for people who are Deaf or disabled generally do not serve the needs of late-deafened and hard of hearing people.
- Most houses of worship and public accommodations lack assistive listening systems, although these devices are reasonable in cost and easy to install.
- Approximately one million people are deaf-blind (with varying degrees of sight and hearing impairment); they are not counted separately but are included in the figures for Deaf, late-deafened, and hard of hearing people according to the degree of their hearing loss and preferred means of communication.
- People who are deaf-blind may be members of either the Deaf or the hearing community, depending on the one in which they grew up; those who were born deaf or became deaf before learning to speak are

generally part of the Deaf community, while those who were deafened after they acquired spoken language and raised in the hearing community usually belong to the latter.

### The Deaf Culture

At the core of the Deaf community is a visual language and its accompanying culture, a set of shared values, modes of behavior, and folklore. Members may be physiologically (*audio-logically*) deaf, or may choose to identify with *Deaf culture*. Children who were born deaf to Deaf parents and acquired sign language naturally through their parents are often referred to as "Deaf of Deaf," and are highly regarded in the Deaf community. This does not mean that Deaf parents love their hearing children less, but having a Deaf child is not considered a tragedy.

Having Deaf parents, however, is not the only way to become culturally deaf. Ninety percent of deaf children have hearing parents<sup>2</sup> and therefore are not assimilated into the Deaf culture from birth. Assimilation is often determined by their parents' choice of communication method and educational placement. Many children now receive a *cochlear implant* along with intensive auditory and speech training to maximize their ability to participate in the hearing community. The Deaf community has strongly objected to cochlear implants for deaf children, believing that hearing parents often fail to recognize the value of belonging to the Deaf community. Conflict may arise in families and the local church over the issue, calling for skilled pastoral care and conflict resolution.

Those who are educated in residential deaf schools will most often learn a form of *English-based sign system* in the formal classroom setting and will pick up American Sign Language from the Deaf children who have Deaf parents and the Deaf workers at the school. Besides language, they will also learn the folklore, traditions, values, and mores of the Deaf culture in these residential schools. Those who are educated in public schools through some form of *mainstreaming* may still become part of the Deaf culture as adults. Often they will marry other Deaf people and become an active part of the Deaf community.

While those who were mainstreamed may feel comfortable in both the hearing and the Deaf worlds, they may feel rejected by both. Because they were raised in hearing families and educated with hearing children, they may feel more comfortable around hearing people and hearing ways. However, they are not totally accepted by the hearing world. As Deaf people, they may feel more comfortable with the Deaf community, but because of their lack of ASL skills and the fact that they do not share the common experience of the residential school, they may not feel totally accepted by the Deaf community either. Rather than living between the worlds, they may choose the world, community, and culture to which they will give their time and energy. If they are able to develop sufficient ASL skills and choose Deaf culture, they will acquire the values, behaviors, and traits of that culture as adults.

For those unfamiliar with Deaf culture, below is a comparative listing<sup>3</sup> of the values held by those who are culturally hearing and those who are culturally deaf.

<sup>2</sup> Figure cited by the National Institute on Deafness and Other Communication Disorders (NIDCD), April 2000. See <http://www.nidcd.nih.gov/health/parents/commopt.htm>

<sup>3</sup> Adapted from Carol Padden's "The Deaf Community and the Culture of Deaf People" and Stephanie Hall's "Train-Gone-Sorry: The Etiquette of Social Conversations in ASL," both found in Sherman Wilcox, Ed., *American Deaf Culture*, Silver Spring, Maryland: Linstok Press, 1989.

### Hearing Culture Values

1. Values speaking ability
2. Values using eye contact sparingly
3. Limits body and facial expression
4. Introduces people by first name
5. Prefers "hard of hearing" in naming self

### Deaf Culture Values

1. Disassociates from speech
2. Requires eye contact
3. Grammatical features of ASL require bodily and facial expression
4. Introduces people by full name, school, and where they grew up
5. Prefers "Deaf" in naming self

It should be noted that culturally deaf people often prefer to attend a Deaf church rather than a hearing church. Hearing parents with deaf children have found that it benefits them and their deaf children greatly if the children attend a Deaf church, since a majority of Deaf people make a commitment to God through a Deaf church setting rather than a hearing one.

### Late-Deafened and Hard of Hearing Perspectives

Few late-deafened and hard of hearing people belong to the Deaf community, but the greater their hearing loss, the more difficulty they have functioning effectively in the hearing community. Because of shame, lack of knowledge about assistive technology, and other reasons, they seldom ask for the assistance that they need.

The general public has many misconceptions about hearing loss. Contrary to popular belief:

- Hearing aids do NOT correct a hearing loss. A hearing aid amplifies sound but can not make it clearer.
- Most late-deafened and hard of hearing people do NOT know sign language.
- People who work with the Deaf community are usually NOT familiar with the needs of late-deafened and hard of hearing people.
- The majority of hard of hearing people are NOT elderly.

The list below compares differences in the adjustment of culturally deaf and late-deafened/severely hard of hearing people.

### Cultural Deafness

1. Healthy sense of identity as a Deaf person
2. Fluent in sign language
3. Support of Deaf community
4. No perceived loss
5. No family/career crises
6. May have difficulty with reading, writing, speech

### Late Deafness/Severe Hearing Loss

1. May be ashamed of hearing loss
2. May never learn to sign
3. Often isolated—seldom part of Deaf community but unable to participate effectively in hearing community
4. Loss of music, activities, social groups, contact with world
5. May have family/career crises with onset of hearing loss
6. No expressive (reading/writing/speaking) problems; receptive communication problems



## Individual Needs

Generalizations are just that—generalizations; what's typical doesn't always apply. For example, some people who are born deaf don't use sign language, and some who are late-deafened do. Although most hard of hearing people lost their hearing later in life, some were born with a hearing loss. Most people who were born deaf have hearing parents, but others have Deaf parents and some come from large Deaf families. The majority of late-deafened people belong to the hearing community, but some have joined the Deaf community. And many people who are functionally late-deafened describe themselves as "hard of hearing." Similar differences are found among deaf-blind folk. In ministry, it's important to ensure that the individual's needs are met.

## USING THIS MANUAL

Because the United Methodist Congress of the Deaf (UMCD) and the National Committee deal with a diverse group of people, this book covers ministries that affect a variety of people with hearing losses. Linguistic lines can be drawn for purposes of discussion, but they are not meant to box people into neat packages. Life is multifaceted and people are complex.

The majority of late-deafened and hard of hearing people—along with many deaf-blind people who developed their auditory loss *postlingually* (after acquiring spoken language) and people born deaf but raised orally—identify with the hearing community. In the U.S., English is their first language. Efforts to minister to these people should focus on providing the access and support that can enable them to participate effectively in their local congregations. In contrast, culturally deaf individuals have their own community based on a visual

language, and efforts to minister to them should focus on ways to connect spiritually through their language and culture. Each annual conference or local church seeking to further its ministry with people who are Deaf, late-deafened, hard of hearing, or deaf-blind will have its own particular point of entrance into these engaging and vital ministries.

Every congregation has older members who are losing their hearing because of aging; many are also losing their sight due to age-related *macular degeneration* (AMD) or other causes. This book will provide information on how to enable such individuals to participate and share their gifts more fully in worship services and other church activities.

Some congregations may want to focus on enabling the participation of people who were born deaf or became deaf early in life. This ministry can take the form of religious education classes for Deaf children or an outreach ministry within the local adult Deaf community. Separate Deaf churches with sermons presented in American Sign Language are popular in the United States. Other congregations may choose to be in ministry with those adults who have lost their hearing later in life and have had to adjust to the reality of becoming deaf. Churches that have an interest in youth ministry may want to focus on the risks of hearing loss in young people because of noise pollution and particularly loud music. Exposure to high noise levels, such as rock music, has led to hearing loss or deafness in as many as five percent of American teenagers.

Whatever the focus of ministry or combination of different ministries with people who are Deaf, late-deafened, hard of hearing, or deaf-blind, this manual provides information to help people get started and to enhance the ministries they already have in place. It covers a variety of topics, including curriculum design and reli-

gious education, accessibility issues within worship and preaching, technological aids, models of ministry, and family and counseling issues. Included are brief descriptions of history and cultural differences, a discussion about languages and communication modes, and, at the end of Part One, a look at the laws that pertain to the rights of Deaf, late-deafened, hard of hearing, and deaf-blind people. At the end of the manual is a list of resources, a glossary, and an audit for congregations to rate their accessibility.

This manual is divided into three separate Parts based on common issues and ministry needs. You may wish to concentrate on only one of the three Parts, but a glance at the entire resource will help you understand the full range of ministry needs of those who are Deaf, late-deafened, hard of hearing, and deaf-blind.

**Part One: Deaf Ministry** covers ministries with those who are culturally deaf either by birth (they were born deaf to Deaf parents) or through acquisition of the Deaf culture. Members of this group may consider themselves bicultural (able to switch between the Deaf and hearing cultures), but they prefer the ease of communication within the Deaf culture. Sign language is crucial to them—both American Sign Language and contact sign language, sometimes referred to as Pidgin Signed English (PSE).

**Part Two: Ministry with Late-Deafened and Hard of Hearing People** deals with those who are culturally hearing. Most were either born hard of hearing or, more commonly, were born with hearing but then lost part or all of it later in life. This Part includes oral deaf people, who were born deaf and learned to communicate primarily through speechreading and technological aids (including cochlear implants) rather than sign language. They are

culturally hearing, and a spoken language (most commonly English in the U.S.) is their first and preferred method of communication—spoken, written, speechread, or (among a small percentage) signed in an English mode.

**Part Three: In Solidarity with Deaf-Blind People** discusses how the church can be in ministry with people who are deaf-blind. As life expectancy increases, local churches are more likely to have members in this category, since the incidence of deaf-blindness is higher in the elderly population.

### **A Note on Identity and Labeling**

Identity and labeling are currently some of the most contentious issues in our society and the communities represented in this manual. As you read it and reach out in ministry to the diverse people who experience hearing loss or deafness, you will undoubtedly discover a variety of identities and labels.

Of course the best labels for individuals are the ones they have chosen for themselves. Our experiences shape how we understand ourselves and talk about ourselves. When people gain more experience and encounter more ideas, they may change their personal labels to meet new perceptions of who they are.

A lively discussion ensues when people of varying identities gather to write materials to educate others who are unaware of many of these experiences. The National Committee feels that the diversity of identities in this booklet is a gift to the church. It is our hope that by claiming our diversity and working together in ministry, we can put aside concerns about labeling and begin building a church that serves and is open to everyone.

## PART ONE

# Deaf Ministry

*D*eaf<sup>1</sup> people (the D is often capitalized when referring to *Deaf culture*), whose main language is the visual one of their country or area, form a separate linguistic group, with their own culture and traditions. Whether their language is French Sign Language or *American Sign Language* (ASL) or one of many other signed languages, Deaf people's affiliation is as a group. The amount of actual hearing loss is not a factor, and members range from profoundly deaf to hard of hearing, just as there are many people who have no hearing who belong to the *hearing world*.

Instead, Deaf people come from a different center,<sup>2</sup> where deafness is normal and the others are those from the larger hearing majority. Being Deaf of Deaf (a Deaf child born to Deaf parents) is valued. Deaf children from Deaf families are respected because of their fluency in the language. A "very hard of hearing" person is someone who is more hearing. A "little hard of hearing" person is someone who has some usable hearing, perhaps being able to use the phone, but is still closer to the *Deaf community*.<sup>3</sup>

This section will focus on the American Deaf culture, whose primary language is American Sign Language. The major transmission of ASL from one generation to another is through *residential schools* for the Deaf, but it is still possible for other Deaf people to pick up the language and folklore, even if born into an all-hearing family whose members never learn sign language. Following is a look at the historical development of Deaf ministry.

## **HISTORY OF MINISTRY WITH DEAF PEOPLE**

The most common written material we have that documents a church's ministry with Deaf people comes from the Roman Catholic Church in Paris during the 1700s. There are earlier documents which suggest that the Roman Catholic Church had been involved in Deaf ministry even before the 1700s, but for the purposes of this book, we will trace Deaf ministry from the Roman Catholic Church in France to the Congregationalists and Episcopalians in New England and finally to our own United Methodist heritage.

### **European History**

When Charles-Michel, Abbé de l'Epee, a French Roman Catholic abbot, inherited the responsibility of teaching the catechism to twin Deaf girls so that they could take their first communion, he became so enthralled with the concept of language and communication in inaudible modes that he eventually devoted his entire life to establishing the first school for Deaf boys. In 1755 he opened his school and in 1776 he published a treatise on a manual code he had developed for the French language called *Methodical Signs*. While the Abbé de l'Epee recognized that Deaf people already communicated in a language of their own (French Sign Language), he wanted them to learn the written French language as well.

After the abbot's death in 1790, Roch-Ambroise Sicard took over as director of the

<sup>1</sup> Terms that are defined in the Glossary on page 83 are italicized on their first appearance in the Introduction and in each Part.

<sup>2</sup> Padden, Carol, and Humphries, Tom. *Deaf in America: Voices from a Culture*. Cambridge, MA: Harvard University Press, 1988.

<sup>3</sup> Padden, 1988.

school. By now the school had graduated Deaf students who were then hired by the school as teachers for the new young Deaf students. Laurent Clerc was one of those promising students who had become an exceptional teacher.

## **U.S. History**

In the United States, the person most influential in starting a ministry of education for Deaf children was a man who had a Deaf daughter, Mason Cogswell, son of a Congregational minister. A wealthy and well-respected citizen of Hartford, Connecticut, Cogswell gathered philanthropists and other people interested in providing religious and secular education to Deaf children. He eventually asked a seminary student, Thomas Hopkins Gallaudet, to travel to Europe and investigate the methods that were being used to teach Deaf children. A neighbor of the Cogswells, Gallaudet was touched upon meeting their Deaf daughter, Alice. Inspired by the Holy Scriptures to bring the Good News of salvation to those who had never heard, he agreed to sail to Europe and eventually found what he was looking for at the school in Paris founded by the Abbé de l'Epee.

Gallaudet convinced Laurent Clerc to move to America and become the first Deaf teacher of a new Deaf school there. Giving up the language and religion of his country, Clerc decided to leave France and accompany Gallaudet back to America. In 1817, the first school for the Deaf was established in Hartford, Connecticut, under the direction of Clerc and Gallaudet. It is important to note that in the 18th and 19th centuries, the Deaf schools that emerged did not just provide a secular education but were firmly grounded in religious ideals, education, and practice. Religious education was fundamental to these schools, and chapel was held regularly.

Gallaudet had four sons. The oldest, Thomas Hopkins Gallaudet, Jr., became an Episcopal priest and started the first church for the Deaf, St. Ann's in New York City, in 1851. The youngest son, Edward Miner Gallaudet, became the founder and first president of what is now Gallaudet University in Washington, DC. It is currently the only liberal arts university in the world specifically for Deaf people.

## **United Methodist History**

The early history of Methodist involvement with the Deaf community began with two Deaf pastors: Philip Hasenstab in Chicago and Daniel Moylan in Baltimore.

Philip Hasenstab started a ministry for Deaf people in the Chicago area when he was teaching at the Illinois School for the Deaf. First licensed to preach in 1890, he would make a trip to Chicago every Sunday to preach to two separate groups meeting in that city. He spent several summer vacations working full-time with the Chicago Deaf ministries until in 1893 he was finally appointed Pastor in Charge of the Mission for the Deaf. He was ordained a deacon in 1894 and an elder on October 8, 1899. The ministry in Chicago was very active. Besides hosting worship services, fellowship activities, Bible studies, and an Epworth League (youth group), the Chicago Temple mission also supported two students at the Cheefoo School for the Deaf in China.

To accommodate the rapid growth of the ministry, Henry Rutherford was appointed as assistant in 1900. He was a graduate of the Illinois School for the Deaf and had attended Gallaudet College. He became responsible for Northern Illinois, Nebraska, Iowa, Missouri, and Kansas—quite a circuit rider! Vina Smith, another graduate of the Illinois School for the Deaf, was consecrated as a Deaconess and also

assisted the Reverend Hasenstab. The book *A Goodly Heritage* is about the life of Rev. Hasenstab and the Chicago ministry. It is written by his daughter, Beatrice Elliott Hasenstab Krafft, and contains original source material from his diaries and personal letters.

Moylan became deaf at the age of four from measles. Except for one sister, his entire family died of tuberculosis. He was then raised at the Maryland School for the Deaf in Frederick, which became his family. Like Hasenstab, Moylan became a teacher who was very active in the Deaf community. He taught shoemaking at the Maryland State School for the Colored Deaf and Blind. He was state organizer for the Maryland Association for the Deaf and helped to found a Deaf insurance society called the National Fraternal Society of the Deaf.

He started his professional ministry by leading Bible classes for men in an old YMCA building in 1895. This was the beginning of the Methodist Mission for the Deaf in Maryland. By 1896, it had moved to the Eutaw Street Methodist Episcopal Church. Moving several times in its history, the church changed its name in 1912 to Christ Church for the Deaf. It was not until 1926 that the congregation finally had a building of its own at Bethany Methodist Church. From 1916 to 1923, Moylan was assisted by another Deaf pastor named John Branflick.

In addition to Christ Church of the Deaf, which was strictly for whites, the Reverend Moylan also started a black Deaf church in 1905, which was called the Whatcoat Mission for Colored Deaf in Baltimore. He started yet another church near Gallaudet College in Washington, DC, which was originally called Waugh Chapel. After Moylan's death, the Whatcoat Mission and Christ Church merged in 1955 under the pastoral leadership of Louis Foxwell, Sr., who was hearing but had Deaf parents and was raised in

Christ Church. It was the first integrated church in the Baltimore Conference.

### The United Methodist Congress of the Deaf

In 1978, the United Methodist Congress of the Deaf (UMCD) held its first official Congress. Several years of leadership training workshops preceded this meeting, however, and 1973 is commonly considered the true beginning of UMCD. Just prior to 1973, Deaf people and concerned ministers made contact with the newly formed General Board of Global Ministries (GBGM) of The United Methodist Church, which agreed to act as a liaison for Deaf ministries. GBGM itself was undergoing reorganization as The United Methodist Church merged with the Evangelical United Brethren Church. One of the conditions agreed upon by the newly-formed church as part of this merger was the elimination of institutional segregation. In 1988, UMCD scored a major success when the General Conference of The United Methodist Church adopted a petition encouraging all annual conferences to establish Deaf ministries within their boundaries.

The time was right for a previously unrecognized and unnoticed group of people—Deaf people—to obtain formal recognition. The history of the Deaf community parallels that of other ethnic minority groups in its search for acceptance as equals in the mainstream world, with services and access to allow Deaf people full participation in daily life and respect for their own unique cultural legacy and differences.

Initially the UMCD was an organization that provided a network of pastors who served in Deaf ministry and a means for other Deaf Methodists to gather for fellowship and worship. The UMCD is still active today. Voting representatives in all five jurisdictions across the country gather nationally every two years on

odd-numbered years. On even-numbered years, some jurisdictions have jurisdictional congress meetings to encourage ministries within their area. Anyone is welcome to attend either the jurisdictional or the national meetings.

## **ACCESSIBILITY ISSUES IN THE LIFE OF THE CHURCH**

Making the church's life and ministry accessible to Deaf people seldom requires much physical change in the building. On hearing the word "access," most people automatically think about physical access—ramps to get into buildings, bathrooms with stalls wide enough for a wheelchair, or doors with push-bar handles instead of doorknobs. In the case of Deaf constituents, however, what must be created is access to communication. This can only be achieved completely if there is a change in attitude on the part of the church's hearing members. Hearing people need to be educated about the gifts and skills that Deaf people can bring to a faith community. If a Deaf ministry is started in a hearing church as some kind of "missionary outreach," Deaf people often remain observers rather than full participants. An *interpreter* is provided for them, but they may not be asked to serve on committees or teach Sunday school or take an active role in United Methodist Women or United Methodist Men.

The church is called to educate itself about the needs and gifts of Deaf people and to treat them as equals. This is key to a strong Deaf ministry. Ideally, hearing people from the congregation will learn sign language in order to communicate with their new Deaf members. They will not depend on the Deaf people to make all the accommodations to the ways in which hearing people communicate. To be in equal ministry together in a *bicultural, bilingual*

situation, both parties will be asked to compromise and to meet each other halfway.

The church can facilitate this process by offering sign language classes for hearing people so they can communicate with the Deaf members in their own language. Hearing people can learn to carry a pad and pen in order to write back and forth with Deaf people when other communication fails.

### **Technological Aids**

For the safety of its Deaf members, each church will want to adapt its fire alarm system to give a visible as well as an audible signal. Special visual fire alarms can be purchased and placed in strategic places so that if an audible alarm goes off, a bright light also flashes. There are many other technological devices that are used primarily in the home but may be required in the church if there is a Deaf person on the staff. Doorbells and telephones can be hooked up to lights within the office so that a Deaf employee knows when the phone is ringing or when someone is at the door.

### **TTYs**

Churches that are interested in a Deaf ministry will need to add some necessary equipment. The first thing that will probably be needed is a TTY (sometimes called a TDD [Telecommunication Device for the Deaf] or text telephone). This device allows Deaf people to communicate by phone through conversion of telephone signals to visible print. The TTY was originally a Teletype machine and the first kind of telecommunication device to be invented. TDDs use all the latest digital technology and resemble typewriters with a visual display. However, TDD is a term invented by hearing people and is not often used within the Deaf community.

A TTY is used in conjunction with a regular phone (direct-connect TTYs that work without a phone are also available). The TTY has a coupler that resembles a cradle on which the phone handset sits. The sender types a message on her TTY, which transmits it by phone. The words then appear on paper or across a digital display screen on the receiver's TTY. When the sender is finished with that initial message, she types the signal "GA" for "go ahead," which means that it is the receiver's turn to type. At the end of the response, the receiver also types "GA." This goes back and forth until both parties are finished and ready to hang up. At this point the signal "GA to SK" is given, meaning "I am done, but if you have any last words, go ahead." The response "SKSK" (stop keying) means that it's okay to hang up. A TTY is crucial to telephone communication between the church staff and the Deaf members. It is also important that a telephone with a TTY be available for Deaf people to use when attending church functions.

### *Telephone Relay Service*

The Americans with Disabilities Act, passed in 1990, established a nationwide telephone relay service that enables TTY users to communicate with hearing people who do not have TTYs. This is accomplished with the help of an operator (referred to as a "communication assistant"), who types the hearing person's spoken message for the Deaf person and voices the Deaf person's typed message for the hearing person. *Voice carryover (VCO) TTYs* are available that enable the TTY user to speak his or her own messages during a relay call. However, VCO TTYs are mainly used by late-deafened people, since many *culturally deaf* people do not use spoken language.

### *Closed Captioning*

For educational purposes, the church may want to purchase a VCR and either a *closed captioning decoder* or a television with a built-in decoder chip. A decoder allows Deaf people to watch closed-captioned videos that might be bought or borrowed for teaching purposes. If the church does not already have a closed-captioned television, a decoder will be needed. All televisions with screens 13 inches and larger manufactured after July 1, 1993, must have a decoder chip. (For more information on the decoder chip, consult the section on "Legal Rights of Deaf People and the Response of the Church," page 33, which deals with the *Americans with Disabilities Act*.)

### *Other Aids*

Obviously, a sign language interpreter, or preferably a pastor who signs, is necessary to make worship, meetings, classes, and fellowship activities accessible, unless the Deaf members have segregated classes and activities. In committee meetings, it is also helpful to provide a *graphic notetaker*. This is a person who writes down the basic topics of conversation, the results of any votes taken, and a running record of the deliberations of the meeting. The notes are written on large newsprint or butcher paper taped to a blackboard or wall so that everyone in the room can follow exactly what is happening. It is difficult for Deaf people to take notes and watch an interpreter at the same time. Graphic notetaking allows the Deaf committee members to get a synopsis of the discussion during the meeting, and afterwards they can copy down any information they need to take home with them.

Likewise, in educational settings where

Deaf and hearing people are in the same class, visual aids are always helpful. Some examples are maps, slides, or overhead projectors—anything that will provide additional visual cues to the topic of conversation. If a Deaf person misses something from the interpreter, the visual aids will provide the additional information. Another option is to videotape the meeting for later translation.

This is true for worship as well. Worship services tend to be very wordy. The preacher speaks and the congregation listens. Other parts of the service, such as prayers, responsive readings, and choral selections, also involve listening. These functions are inaccessible to most Deaf people except through a third person, the interpreter. There may be banners and other visual symbols placed throughout the sanctuary, but when Deaf people have to focus their attention on an interpreter to understand the words, their eyes can't wander to look at other visuals in the environment.

Use of dramatic and visual arts in the actual worship service helps communicate in ways that words alone cannot. Liturgical dance, drama, slides, and concrete objects all enhance the worship service for the hearing members as well as the Deaf. Remember that the culture, language, and worldview of Deaf people are based on sight and touch, not sound. Visual and experiential activities make worship more accessible for the Deaf constituency. Deaf people tend to appreciate particularly the passing of the peace as a time to move, hug, touch, and greet the gathered community.

Cultural differences need to be recognized so that Deaf members are not judged according to the hearing culture's values. Since members of the Deaf community often live and work isolated from other Deaf people throughout the week, they consider any gathering a time of

sacred celebration. When this occurs on Sunday mornings at church, their interest in communication and their joy at being able to express themselves in their own language are paramount. Often Deaf people will be signing to each other long after the prelude music has started and all the hearing people have moved into a time of quiet meditation. It is true that most do not hear the prelude music and do not know that it has begun, but it is also true that Deaf people think of communication as a cherished means of God's grace.

Likewise, during communion, as everyone walks forward to partake of the elements, it is not uncommon for Deaf people to sign to each other. This is not evidence of disrespect for a sacred moment, but rather a sharing based on the belief that personal interaction and communication are valuable in and of themselves, especially when they are so often denied at work or in their neighborhoods during the week.

Hearing people may have a very difficult time understanding this dynamic and may want to impose their own cultural values on Deaf members. Learning from each other is crucial at this point, and both parties may need to compromise. An outside Deaf person trained in linguistics or anthropology might be able to help the Deaf and the hearing constituents understand each other.

One last word about access: the issue of inclusive language for women and people of color has been a topic of conversation in the general church in recent years. Deaf people are also beginning to identify words and phrases that are exclusive of their reality and experience. To "hear" the "voice" of God "calling" is really a metaphor from the hearing world for a kind of communication that takes place in silence. Our hymns and liturgies are full of other metaphors drawn from the experiences of



the hearing. Deaf people may find it hard to relate to this kind of language and may feel excluded. If you have a Deaf ministry, use language carefully and sensitively. Balance out oral and aural metaphors with visual or other kinds of metaphors. Try to relate some sermon illustrations to the realities of the Deaf members of the congregation. Again, attitude is crucial. Once we begin thinking inclusively, we also begin acting inclusively, and soon being inclusive becomes a way of life for us and not a chore performed according to a checklist.

#### **"Deaf/Hearing Unite: the McHargue-O'Donnell Story"<sup>4</sup>**

As my father walked me down the aisle to be married, I focused intently upon the face of my soon-to-be husband, Scott. However, I couldn't help but notice the people to my right, signing low and quickly, the typical wedding comments about the church, my dress, etc. To my left, there were whispered comments of the same nature. This walk down my wedding aisle has become analogous to my walk, forevermore, between the Deaf and hearing cultures.

It all began in the summer of 1986. My mother and I went to see a play called "Talking With." The play consisted of a number of monologues by different female actors. One monologue was delivered in American Sign Language by a voice interpreter. I was captivated by the way this woman made her arms and fingers fly through the air; it looked more like a graceful dance than scripted speech to me. I read in my program that this talented actress was Cathy Haas, a Deaf lecturer at Stanford University, where I was about to begin my junior year in college. I decided then and there that I must enroll the following quarter!

I enjoyed every second of the beginning

ASL class that I took. Cathy has a gift for teaching, and I loved the language and the presentation of it. Cathy also told many stories of her experiences growing up deaf, which piqued my interest from a sociological perspective as well. I majored in sociology, since sign language was not an option at that time, but I continued to take every sign language class I could.

As I was finishing graduate school, instead of immediately making the transition into teaching, I decided to continue studying sign and Deaf studies. I followed my heart and re-enrolled in Ohlone College, in Fremont, California, determined to learn the language and culture.

I remember one event at Ohlone as if it happened yesterday. I was taking a class by Ella Mae Lentz, a renowned Deaf poet, and it was just before Christmas break. Since our class was small that day, she decided not to start a new lesson but to tell stories instead. We were so lucky. Ella signed "'Twas the Night Before Christmas" for us. I had memorized this poem when I was only three years old. In fact, my grandparents couldn't believe I could recite it verbatim at such a tender age. Here I was, 18 years later, captivated, "listening" to it with the delight of a toddler! I realized this was the first time I really, truly understood the text. I had mindlessly recited the ballad for so many years without ever really thinking about the words or their meaning fully. I had it down orally and aurally, but the visual presentation made my understanding complete for the first time.

As the years went by, I improved my signing and lipreading skills. I worked as an interpreter at a local community college. Then one day I met a new Deaf student, became his interpreter, and changed my life forever!

I walked into the afternoon sociology class I was scheduled to interpret. I had with me the

<sup>4</sup> This was written by Randi McHargue O'Donnell. (Note that marriages between culturally Deaf people and hearing people are relatively uncommon.)

list of the three Deaf students I was to interpret for and met two of them. They sat in the front row, just in front of my chair, as was customary. The instructor entered and began his lecture. As I expected, the hearing, non-signing students looked my way with fascination. Halfway through the lecture, as I also expected, the novelty of having an interpreter in the room had worn off, and the hearing students started to give eye contact to their instructor instead of me! That is, all but one student, other than the two Deaf students up front. Way up in the very back row of this auditorium-style classroom with graduated seating, one male student stared at me intently. He stared and stared and quite frankly was making me very uncomfortable. After noticing this was continuing, the teacher gave the class a short break and I, violating all interpreter ethics, looked at this man and signed and voiced to him angrily, "Are you Deaf?" He nodded affirmatively, and that was how I met my husband for the very first time!

You see, Scott grew up in an all-Deaf family. In fact, he is third-generation Deaf. He attended Deaf schools, including Gallaudet University, the only all-Deaf undergraduate institution in the world. Scott had decided to take a class at De Anza, the local hearing college, and this was his first experience using an interpreter. He had not realized that there was a protocol of front-row sitting, allowing the interpreter to get visual feedback instantly from her students while still being able to hear the instructor. Scott chose to sit in the back row because he is tall and didn't want to block the view of others.

Only six weeks into that quarter, we were already falling in love. Though there was no written rule prohibiting Deaf students from dating their interpreters, both of us were a little leery of starting a relationship which, if it

soured, would have to be played out in the classroom. Another factor was that he was Deaf and I was hearing. I hadn't chosen a sign language interpreting career to find a mate. Scott, too, certainly had had interactions with hearing people, but he had never dated a hearing woman before. So we were cautious.

I worried about how Scott's family would react to me. While I was at Ohlone, my more militant Deaf teachers would preach that an all-Deaf family would never accept a hearing person into it by marriage. They couldn't have been more wrong. Scott's family welcomed me with open arms, literally and figuratively. The first day I met Scott's father, Bob, I thought he was slowing his signs for me. He continued to sign at a snail's pace, so I believed he was patronizing me, this little hearing novice signer. He then turned toward his other children and signed in the same slow fashion. I realized that Bob's childhood oral training had stunted his ASL growth a bit, and that was the speed with which he always signed. Scott's mom and siblings did have to slow down and sign more English-y to me, but they were always very patient and understanding.

My family was the more hesitant to accept Scott fully. Scott is younger than I am and had a few more classes to go before finishing college. There was also the language barrier. My brother immediately signed up for an ASL course, and today, he and his wife communicate beautifully with Scott. My mom talked to Scott mostly about food, since those were the first signs she learned. She complained that some signs like "apple" don't look the way you do when you're eating one. She would offer him a mimed version of eating an apple instead. Scott reminded her that he didn't invent the language. My father began his first discussions with Scott around sports. Sometimes when I would leave the room, I

would return to find them talking in "referee language." I had no idea what they were saying, but they seemed to understand one another perfectly. My family continues to make an effort to include Scott in activities and conversations as much as possible.

We always knew we would get married. It was an unspoken (and unsigned) understanding between us. I remember one instance early in our dating life when we were at our favorite hangout, a restaurant in Palo Alto, California, with an outdoor patio and waterfall. As we sat there talking, Scott said out of the blue, "You know, if we get married and have children, there's a good chance they will be Deaf. Would that bother you?" Though surprised by the statement, I responded, "If deafness were a problem for me, would I be dating you?" And that was the end of that.

Our wedding was an eclectic mix. Not only did we pick the Stanford Chapel for its combination of architectural styles and types of art, we filled it with friends and family equally different. Scott's side of the church was full of Deaf and/or signing guests and my side was entirely hearing (except for aging family members!). We had one sign language interpreter facing Scott's side of the congregation, as well as one up with us so Scott would understand what he was promising to do. At the reception, we tried our best to make the evening accessible and enjoyable for all. We hired a group of performers called *Half 'n Half* to entertain. All of the members were the hearing children of Deaf adults (CODAs). During the musical numbers, they signed and danced to the beat. Our hearing guests were especially intrigued by their mode of communication and watched with big eyes. Many of our Deaf friends commented that this was one of the few venues they'd attended with so many hearing people

who were trying to communicate with them. That made us feel relieved. Even the entertainers said they could feel the love in the room.

Not everything in our marriage has been wine and roses, I'll admit. Sure, like other couples, we have money frustrations and gender misunderstandings, and we also butt heads like two stubborn first-borns do. However, some of our problems do stem from a difference in culture. I know I get frustrated having to operate in my second language at home. It's harder for me to articulate my feelings in sign language and sometimes, in the middle of an altercation, I quit signing altogether and start screaming. (This must look pretty silly to Scott!) I am sure that Scott also doesn't like to have to be interpreted to when we go out into some hearing environments, either. As a white male in this culture, he gets treated with the utmost respect in public, that is, until people realize he is deaf. At that point, his status plummets—you can actually feel it. That's got to be very hard for him. Also, there has been the problem of friends. Though they are sweet, wonderful people, we spend very little time with what used to be my hearing group of friends. The problem is, when we go out with them, I have to interpret what is said into sign and also voice what Scott signs. I am so busy trying to include him that I lose my own voice and can't really participate. Going out with Deaf or signing couples is a lot easier for us because we can both be ourselves; however, I still have to operate in my second language, so I don't feel as witty and articulate as I'd like to be.

One saving grace has been our ASL play group. This is a loosely structured group of parents and kids who get together about once a month for play dates. Some of the parents are Deaf, some of the children are Deaf, and there are a lot of us hearing signers as well. What's so

great about this group is that everyone is patient, kind, and trying to communicate together while having fun. We know we are making lifelong friends with these folks and feel very lucky about that.

One of the play group's members is a little Deaf boy named Vitya, adopted from Russia by church friends over four years ago. He has become like a little brother to Scott and accompanies us to many of these functions as well as to camping trips and parties. It's great for Scott to have someone to do "boy things" with and great for Vitya to have a Deaf male role model. They even look alike!

We have two hearing daughters, Molly and Kelly. They are both considered CODAs, and we are trying our best to raise them in a bilingual, bicultural household. Whenever their Dad is home, we sign together. When it's just us girls, I voice exclusively or voice and add signs in an English order. At only two years of age, Molly can understand anything her Dad signs to her. Her responses, however, are typically in spoken English. Luckily, Scott has become a good lipreader. This concerned us initially, but friends have assured us that her signing will catch up eventually. She's just sorting everything out. Molly has great facial expressions and miming abilities from her exposure to ASL. We think this has allowed her to pick up a great deal of Chinese at her day-care program. Kelly is only four months old, but at her recent doctor's visit, her healthcare provider was amazed at her visual tracking ability. Could this be because we sign to her so much? I think so!

Fast-forward to the future: when their father, Scott, walks our daughters down the aisle on their wedding days, it won't matter to us if their partners are Deaf or hearing. What will concern us is the way they're treated. If their spouses

make our girls as happy as Scott has made me, they will have both of our blessings.

## LANGUAGE ISSUES

American Sign Language is the natural language of the Deaf community. It is not based on the English language; it has its own syntax, grammar structure, idioms, and vocabulary (lexicon). The important thing to know about American Sign Language is that it is a complete language in and of itself. It communicates through motion and position of the body in space. It is a "manual" language in the sense that the hands play an important role as they make the signs, but the eyes, eyebrows, shoulders, mouth, head, and body stance are also contributing factors to the execution of ASL. They convey what we often think of as "tone" and "inflection," as well as grammatical markings. It is not an easy language to learn, since it has many complicated features that English does not have.

In addition to American Sign Language, there are a variety of *manual codes of English* that are used in America today. These are generically termed "signed languages," but in reality they are not languages in and of themselves. As signed forms of the English language, they vary in how faithfully they reproduce English.

*Seeing Essential English* (SEE I) and *Signing Exact English* (SEE II), which adhere very strictly to the rules of English grammar, are being taught in many schools today, but the system most commonly used within the Deaf community is a *contact language* (a *communication mode* that evolves whenever two cultures and two languages come into contact), sometimes referred to as *Pidgin Signed English* (PSE) or *contact sign language*.

While contact sign language functions on a

continuum between exact English and ASL, it basically borrows vocabulary from ASL and grammar from English. In this way a person can simultaneously use sign language and speak (or lipsynch) in English. Another common term for this phenomenon is *simultaneous communication*. However, in reality, one language often suffers when two languages are used at the same time. Voicing in English can cause the sign language to become disjointed.

American Sign Language and contact sign language are the two most common communication modes that exist within the population under consideration in this Part. For many within the Deaf community, English is a second language. They may have a good enough command of English to get by in everyday life, but they would be totally lost in a sermon. Understanding the language and communication modes of the Deaf people within the congregation or community is crucial to a church's approach to Deaf ministry.

## INTERPRETER ISSUES

Sign language interpreters are a big factor in almost every aspect of Deaf ministry. Hearing people equally need an interpreter because a nonsigning hearing person cannot communicate with a Deaf person without an interpreter. Even pastors who sign for themselves and have interpreting skills will often use sign language interpreters so as not to confuse their role as pastor with their role as interpreter. For churches with interpreted ministries, the sign language interpreter is crucial. Finding the right interpreter is often a complicated task. More often than not, no search is made for the best possible interpreter; rather, some person with signing skills usually "falls into" the job. Especially in the religious domain, volunteer interpreters, or church peo-

ple who know some sign language, will be utilized rather than certified professional interpreters. This is almost always the wrong approach to providing interpreted ministry.

On the one hand, Deaf people deserve a good, qualified interpreter who is fluent in sign language and can also *code switch* to the other manual codes of English when requested. To be professional, an interpreter should follow the *Code of Ethics* established by the *Registry of Interpreters for the Deaf* (RID) and have certification from RID, the *National Association of the Deaf* (NAD), or the state.

On the other hand, interpreters often become an active part of their church community and committed to Deaf ministry. It is crucial that interpreters be knowledgeable about the religious concepts that are expressed in the Scriptures, the hymns, the sermon, and other parts of the worship service so that they can interpret these accurately. In addition, they must know the range of religious signs used by the particular denomination and local church.

Finding someone who fills both requirements within the given budgetary constraints is often impossible. Therefore, many churches are forced to make a choice between the two. The commitment to a certified professional interpreter is often compromised in favor of someone who is committed to the ministry and is active in the local church. This decision is not always intentionally made. Because of budget problems and the availability of a willing "volunteer" or someone who will come "cheap," churches will sometimes choose an interpreter without consulting the Deaf members. Such a decision not only lessens the quality of interpreting but also sends a message to Deaf members that their input and involvement is not encouraged in decision making.

When deciding to establish an interpreted ministry, take the selection of an interpreter

very seriously. Don't just let it happen. Discuss the issues from the beginning. Intentionally set some goals and allow the Deaf members to make decisions about what is best for them. Make it clear that one of the goals is to raise enough money or add enough money to the church's budget to pay an interpreter. Using a volunteer interpreter will often sabotage a ministry by leading to frustration among Deaf members, who may then leave the church.

If you belong to one of the lucky churches that have in their congregation someone who is both a certified professional interpreter and active in the church's ministry, then rejoice. This person should be paid, whether or not she is willing to work on a volunteer basis as part of a tithe to the church. Pay for the service and let the interpreter decide whether to give the money back to the church. In this way, the church takes financial responsibility for making its services accessible to its Deaf constituency, and if this interpreter should leave, there is money already in the budget to hire a new interpreter immediately.

People with dual qualifications often find themselves called upon to play roles other than that of interpreter. If the hearing pastor does not sign, often the interpreter becomes teacher, counselor, hospital chaplain, and even pastor for the Deaf constituency. The interpreter may be called upon to teach a Deaf Sunday school class, visit a Deaf person in the hospital, or be the informal counselor for the Deaf members, since the pastor seems inaccessible to them. This is not the role of the interpreter. It is inappropriate to force such a situation on Deaf people. They have a right to a trained pastor, and the interpreter has a right to the role he or she is trained for.

Make it clear from the beginning what the Deaf people's expectations of the interpreter are

and what their expectations of the pastor are. If an interpreter becomes overworked and depended on for functions other than interpreting within the Deaf ministry, he or she may soon become burned out and leave. That is not what either party intended when the ministry was established. Keep communication open and make the expectations and job descriptions clear.

Pastors and other staff members should work closely with the interpreter and develop a good working relationship. The interpreter needs to know hymns and Scripture texts in advance so that he or she can prepare for the Sunday morning worship. Interpreters may also want an outline or copy of the sermon if possible. They may have suggestions about language that will save the Deaf constituency from feeling alienated by the service. The church staff and the interpreter should agree on the best place for the interpreter to stand in order for the Deaf members to be able to see both the interpreter and the speaker at the same time.

Working with the interpreter as part of a ministerial team will help alleviate problems down the road. If an interpreter who is well loved by the Deaf members becomes frustrated and takes a job at another church, they may also move to this other church. It is not uncommon for Deaf people to follow an interpreter from church to church, because it is often harder for them to find a good interpreter than a church that they enjoy attending.

One of the hardest issues an interpreter faces is which language and/or communication mode to use. If the Deaf constituency utilizes a variety of communication modes, controversy may arise as to which should be used. Should the interpreter sign in American Sign Language to the best of her ability, or should the interpreter sign in some mode of contact sign language close to ASL or closer to English while simultaneously

lipsynching the English words for those who also *speechread*? This is not an easy question. The answer should be agreed upon by members of the Deaf constituency, or some of them may opt to go elsewhere.

The choice of language should be decided before an interpreter is hired, since the interpreter must be comfortable in the language chosen. However, this decision may have to be renegotiated as new Deaf people join. It is always wisest from the beginning to find an interpreter who is comfortable in all the language modes and able to code switch between them.

Because of the *multilingual* nature of the Deaf community and the financial inability of most congregations to hire more than one interpreter, many churches' Deaf ministries will target one particular population within the Deaf community so that this controversy doesn't arise. For example, one church may focus on the culturally deaf population and hire an interpreter who communicates in American Sign Language. Another congregation may target the late-deafened, *culturally hearing* population and (for those who know sign language) use an interpreter who signs in a form of contact sign language while simultaneously lipsynching the English words so that people can speechread as well.

## **COUNSELING AND ADVOCACY ISSUES**

The counseling issues that arise within the Deaf community are very similar to those of any cultural or linguistic minority. The Deaf are an oppressed community without access to many public services. They do not communicate in the dominant language, which causes communication problems in every aspect of their lives.

Deaf people require the same kinds of counseling that hearing people need. Premarital and marriage counseling, baptism counseling, and new membership education and orientation are needs common to all. The problem of how to make counseling accessible to Deaf people is the main difference.

There is often a greater need for advocacy because those who were born Deaf are a linguistic, cultural minority, and society does not know how to deal with the Deaf community. Problems arise when Deaf people go to interview for a job and employers don't have TTYs or interpreters. Deaf people who are admitted into a hospital need an interpreter, but the hospital may not provide one. Frustration increases when a Deaf person has to deal with agencies such as the Social Security Administration, courts, or social services. Services that are available for hearing people may not be accessible for Deaf people. There are laws that require government agencies and public facilities to be accessible, but these laws are often ignored or left unenforced. Churches can advocate for the Deaf community by being role models and insisting that public and government services be made accessible.

Unique issues arise in families that have a Deaf member. If one spouse is Deaf and the other hearing, communication can be difficult. Extra care should be taken in premarital counseling to explore some of the difficulties that can arise.

Generational communication problems between parents and children exist in all families. However, when parents and children use two different communication modes, if not two different languages, arriving at mutual understanding can become even more difficult. Approximately 10 percent of Deaf people are born to Deaf parents and grow up in a family where everyone uses the same language.

However, 90 percent of Deaf people are born into hearing families and 90 percent of the children of Deaf parents are hearing. This creates two separate situations that require sensitivity regarding communication issues: hearing parents with Deaf children and Deaf parents with hearing children.

Hearing couples are often both devastated and relieved when they find out their child is deaf. They have known something was wrong and may have subjected the child to a variety of tests and visited several doctors before they learn that the diagnosis is deafness. They are relieved that they finally know what is "different" about their child, but at the same time they experience guilt and crushed dreams. They try to envision how their child will grow up, though often they have never met another Deaf person in their lives. (Because newborn infant screening is now coming into use, parents will often receive the diagnosis of deafness when their child is born.)

Parents are swamped with advice from a variety of professionals encouraging them to follow one philosophy and method of communication or another. They have several choices, such as the oral method (speaking and speechreading only, with the use of hearing aids, cochlear implants, or other technology), American Sign Language, Signed English with spoken English simultaneously, and *cued speech*. Parents are encouraged to learn the method of communication they have chosen for their child in order for the family to communicate at home.

A late diagnosis in the preschool years often results in extreme frustration for the child. The child wants to communicate but doesn't have any language with which to do so. Such children may become "physically aggressive" and start "acting out." Hearing parents

feel their own frustrations and don't have any experience in dealing with a Deaf child. Both the parents and the child's language skills are limited in the beginning, and unfortunately the child's language acquisition is often faster than that of the parents. This is true especially if the child begins to attend and live in a state residential school for the Deaf and is only home on weekends and holidays.

The church can be an advocate for hearing parents of Deaf children in a variety of ways. It can provide space where a support group can meet. There are probably other parents in the same situation who would be helped by getting together to share stories about how they've handled different situations. The church can also sponsor educational workshops and meetings so that parents can receive information from the Deaf community and get to know Deaf adult role models for their children. If the church has a ministry with Deaf adults as well as Deaf children, it might be possible to develop some kind of "adopt a friend or grandparent" program. Deaf adults can be paired with Deaf children, while the hearing children of Deaf parents can be paired with the hearing parents of the Deaf children. In that way, the children will have adult role models with advanced language skills who can interact with them as they are growing up.

Deaf parents with hearing children usually know immediately whether their child is hearing or deaf and adjust accordingly. Their hearing children will learn American Sign Language from them as infants. As the children grow older and begin interacting with other children in the neighborhood and later in school, they will learn English. It is not uncommon, however, for hearing children of Deaf parents to need speech therapy in their early elementary years. Unfortunately, most school systems do not recognize



that for hearing children of Deaf parents, English is often a second language.

Communication usually breaks down (as in most families) when the hearing children become teenagers and begin to develop their own identity. They were raised in the Deaf culture, have attended hearing public schools, and are at the stage where rebellion is normal. Sometimes they sneak out of the house at night because their parents can't hear them. Sometimes they play exceptionally loud music for the same reason.

Parents can use the support of the church during these times. It is helpful for their hearing children to become active in youth group activities so that they will have hearing role models. They need to feel good about being bilingual and bicultural rather than embarrassed because they are "different" from their friends. Some churches have established a ministry just for hearing children of Deaf parents and offer discussion groups, outings, and support for them.

Children of Deaf adults have their own special needs and gifts to offer the church community. By the time they become adults themselves, some may have acted as mediators between the hearing world and the Deaf world most of their lives. Many become interpreters as adults and maintain the role of mediator between the two worlds. Others feel as though their lives were not as good as it should have been and wish to remove themselves from the Deaf world entirely. The church should be sensitive to their needs along with the needs of the Deaf ministry. It would not be fair to assume that the hearing children of Deaf parents will volunteer to act as interpreters. They too need a life of their own. If interpreting is the career they have chosen, treat them as professionals and pay them.

### "The Search for My Identity"<sup>5</sup>

People who meet me today have difficulty visualizing my many years of adjustment to deafness as I searched for a new identity as a Deaf individual. My story reflects the state of education at the time I was growing up. Today American Sign Language is accepted as a separate language with its own culture. Today we have sign language interpreters at school to allow us to understand the material presented. When I was growing up, things were very different.

I wanted to be like everyone else growing up, even though I was Deaf. I was unconsciously unaware of the fact that I was deaf. My parents were also in denial, telling me I was hard of hearing. The truth was that I was a Deaf child who did not get anything from the classroom assignments and who did not understand what was going on.

Today, my parents still feel guilty because I am deaf and they feel responsible because my mother had *rubella*. They wanted me to be with the hearing society no matter what the lack of communication was, but are now starting to accept me for who I am: a Deaf woman.

The first school my parents placed me in was the John Tracy Oral School for the Deaf in Los Angeles, California. I stayed there for two years, 1965 and 1966. I was three years old when I entered the school. There was no sign language at the school. All communication was spoken. I didn't understand anything. I couldn't even understand the other Deaf children when we came together in preschool groups. We spent a lot of time working one on one with the speech teacher. I remember the speech teacher slapping my face. I think it was because I didn't pronounce the word "soup" right. I didn't like John Tracy Oral School.

Later, my family moved to Florida and my

<sup>5</sup> By Jill Grimshaw.

parents wanted me to be mainstreamed. At that time there were no interpreters, no Deaf programs, no notetakers, and no one knew that I was a Deaf child. I started first grade with no support other than a heavy body-worn hearing aid. It made me feel ugly and my glasses with thick lenses did not help either.

I hated the hearing aid. It consisted of a box strapped to my body and cords that stuck out of my ears. I also wore the ugliest glasses with thick lenses to help my vision. I was shy, uncomfortable, and frustrated. The body aid hurt my ears and my chest. I would take it off and complain to my teachers. The first-grade teachers always sent me to the principal's office for not wearing my body aid. The principal spanked me with a long, wooden paddle and would send me to the sick room where I stayed by myself for about three hours until school let out. I was free until I got off the school bus and went home, where my mother would spank me again because the principal called her about my not wearing the body aid.

If I didn't go to my speech teacher's room, I would get spanked again. This type of abuse continued until the second half of second grade. The worst part was being shut away by myself. I would cry and pray for someone to assist me. That someone today is called a sign language interpreter, but at that time all I knew was that I needed help in understanding what was going on.

I continued school fully mainstreamed, with no interpreter. I still struggled with wearing and refusing to wear the body hearing aid. I ran away from home and made a lot of trouble. I was isolated and unhappy. When I was 10, the school board let me wear one hearing aid in my left ear, which was better.

At the age of eleven, I started playing tennis and running. I realized I had good athletic

skills. I still had many hardships in school. When I was in sixth grade, my English skills were on the fourth grade level. I did have a friend who sat next to me and always helped me. She would try to get me to say the Pledge of Allegiance faster so that I would be talking at the same time as the rest of the class. Everyone would start laughing if I didn't say the lines correctly or at the right time.

In my middle school years, I got all D's and F's. It was at this time that the school recommended a Deaf program and my parents finally agreed. After Christmas break, I entered the program and continued learning sign language there.

My first experience with sign language, however, came during the summer prior to entering the Deaf program. I was invited to a Deaf pool party. I didn't know sign language at the time and didn't know how to communicate with all these Deaf kids. One Deaf girl from the St. Augustine School for the Deaf was visiting and noticed that I was alone. She introduced me to the alphabet and some basic signs. We became friends and she continued teaching me sign language for the rest of the summer.

In 1979, I entered high school and finally got a full-time interpreter. As a ninth grader, I was on the sixth grade level in reading. But I did have a Deaf education teacher in addition to my mainstream classes, and she taught me the correct grammar and math skills that I lacked from all those years of not understanding.

School improved. My personal life did not. I needed to communicate about my problems growing up and work through those issues, but I did not have anyone to help me. So I tried to help myself. I began experimenting with alcohol in high school and also had an eating disorder from age 15 to 19.

I did find a Deaf community after I gradu-

ated from high school and began attending the National Technical Institute for the Deaf. I had a Deaf roommate. There was a Deaf cafeteria. The communication was wonderful.

Majoring in technology did not work well, however. I did better when I enrolled in Gallaudet University and majored in English. My social world expanded with Deaf people and Deaf culture, which I found fascinating and fulfilling.

I also spent time working, as I felt the need to develop a sense of independence and self-sufficiency. The Deaf Service Center in Tampa, Florida, arranged for an interpreter to help me with job training at IBM, and I entered the world of computers. This helped tremendously with my ongoing depression. It lifted and the world looked bright again.

Still I had ups and downs during this period. I often smiled to make everything seem okay. Because of my strong participation in sports, people admired my spunk. I was often out doing something to keep me busy. But I was not content. I was miserable. I missed not knowing who I really was. I never liked church because I missed out on the enjoyment of listening and singing and all the things people do in a hearing church.

I still had problems communicating at home and dealing with my feelings and unresolved anger. My parents wanted me to be oral, but my mother did start learning some sign language. Still, communication at home was horrifying for me. So many times I slept at houses of friends in Tampa so that I would not have to go home. I missed the Deaf community that I had been involved with at college. Everyone was hearing. I felt confused and paranoid. I began drinking so heavily I had no idea where I was heading in life. Drinking and smoking cigarettes led me to become more paranoid. Life was drifting away from me.

In 1997, I tried to kill myself by overdosing on all of my prescription pills. The phone rang. It was a friend who wanted me to join her next alcohol party. She had just tried to kill herself with a knife by cutting her veins in her legs. Now I wanted to try.

But thanks to an intervention, an ambulance and police cars arrived at my home. I had locked the entire house and shut the blinds. My blood pressure was going down. I was taken to a regular hospital and then transferred to a Deaf unit. I refused to talk to anyone. I struggled with my fists not to listen to the nurses. I wanted to die.

After many sessions with counselors who knew sign language, I was able to begin to share my experiences growing up. I began to understand the abuse I had suffered through and also began to understand that I had a disease called manic depression. I began the healing process for real this time.

Today, my problems are not solved. Everyone has problems in life! But my self-image has been restored and I am a busy contributor to life. I graduated from the University of South Tampa in Florida with a degree in English and am working with computers again, this time for the government. I am active in sports and have a good relationship with my family. I am also involved with the National Committee on Ministries for Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People.

I know who I am today and no one can take my identity away from me. I am Deaf.

## MODELS OF DEAF MINISTRY

For those interested in starting a Deaf ministry, there are many models within The United Methodist Church that can provide some guidance. Each ministry should be unique, based on its own local constituency, geographic location,

trained personnel, and particular interests. It is important that lay people as well as clergy take leadership in developing such ministries. The support of clergy makes Deaf people feel that they are truly a part of the congregation and not just on the fringes. However, most pastors move on to new appointments at some point or other in their ministry. Therefore, lay commitment is also important so that a Deaf ministry will not fold when a new pastor arrives who is not familiar with Deaf ministry.

The following models are not meant to be exhaustive or to restrict creativity. Annual conferences and churches are developing new models every day.

Currently within The United Methodist Church we have Deaf churches, a variety of models for interpreted ministries, campus ministries, itinerant conference staff people, educational ministries within residential Deaf schools, youth programs, and Deaf camps. If you are new to Deaf ministry, these models may help you focus your own goals.

### **The Deaf Church**

For a variety of reasons, members of the Deaf culture often prefer a Deaf church. Here they can design their own worship style based on their visual/spatial language and their unique needs and abilities. Deaf members can act as chairpersons of the various committees and decide the educational program of the church as well as its outreach ministries.

Within The United Methodist Church in America, there are currently two Deaf churches. They are located in the Baltimore-Washington Annual Conference. These churches are chartered as separate congregations with the complete committees and budgets required by the *Book of Discipline*. Both are funded in part by congregational giving and subsidized as

mission churches of the Annual Conference. Services are conducted in a variety of linguistic methods aimed at conveying the word of God to the entire congregation. American Sign Language, contact signing, tactile signing, real-time captioning, and oral interpreting can all be used during any one worship service.

One of these churches, Christ United Methodist Church of the Deaf, also hosts a Deaf Shalom Zone program. Shalom Zones were created by churches and faith-based communities in response to urban violence and poverty. The Deaf Shalom Zone has claimed the Deaf community of Baltimore and the five-county zone around the city as its territory. Within this territory, the Zone workers aim to improve the lives of struggling Deaf people by providing connections, advocacy, and services that are otherwise not offered. Parenting classes, Alcoholics Anonymous groups, hospice care, transportation, tax preparation, and financial counseling are just part of the services being developed by this ministry. The Shalom Zone is coordinated by a missionary of the General Board of Global Ministries under the 10-10-10 missionary program.

Deaf churches in the Baltimore-Washington Annual Conference provide outreach ministries to the state schools for the Deaf through religious education classes, and they cooperate on a conference-wide summer camp for Deaf children. In addition, they provide leadership for churches and interpreters within the conference who are interested in establishing interpreted ministries.

At the present time, there is one ordained culturally deaf person in Deaf ministry in The United Methodist Church, serving as campus minister at Gallaudet University. The United Methodist Congress of the Deaf and the National Committee on Ministries with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People are working to increase the num-

ber of ordained pastors who are culturally deaf or have other types of hearing loss.

Each Deaf congregation functions within its own geographic region based on the Deaf population in that area. The language it chooses to use reflects both the skills of the pastor and the needs of the community.

The constituency of these congregations is not very homogenous. Within any one of them can be found some Deaf individuals who communicate primarily in American Sign Language, some who use contact sign language, some who speechread (lipread) and use Signed English as a supplementary communication aid, and some hearing family members who may or may not know any sign language. In such a multilingual context, it is very difficult to choose one language or communication mode that is completely understood by all.

Moreover, Christ United Methodist Church of the Deaf in Baltimore is *multicultural*. About half of its members are black and Deaf. It has been recognized that black Deaf people have their own variation of sign language that developed when the schools were segregated. In many ways, black Deaf people are trilingual, since they usually know "Black Sign Language," American Sign Language, and some form of the English language.

In spite of the linguistic and cultural challenges faced by Deaf churches, they are preferred by those Deaf people who want to play an active role in the worship design of their faith community and want to serve on the decision-making bodies of the church. In the Deaf church, Deaf people develop leadership skills and take responsibility for all aspects of the life of their church. They must also struggle with what it means to be inclusive when their membership is multicultural and multilingual.

### The Deaf Congregation within a Larger Hearing Church

Other conferences have developed their own unique ministry and created a Deaf congregation within a large metropolitan church. This model functions in many ways like the Deaf churches listed above.

A Deaf ministry that was started at a hearing church may eventually evolve into a separate Deaf congregation within the large hearing church. This congregation does not have a pastor who is officially appointed to it but rather is served by a Director of Deaf Ministry who is fluent in sign language and paid a part-time salary by the hearing church. The worship itself is designed specifically for the Deaf congregation. One of the pastors of the large hearing church acts as a liaison with the Deaf congregation.

The congregation functions as do most other Deaf churches. The service is conducted in both voice and sign language, *reverse interpreters* are used when needed, and lay people are active in worship leadership. The Deaf congregation meets in the facilities of the hearing church and functions as a separate entity. It has separate Sunday school classes, fellowship activities, and a Deaf Commission that coordinates the various task forces needed for the continued operation of the ministry. However, since it is not a separate United Methodist church, it does not have all the various committees required by the *Book of Discipline*.

The church may provide childcare for preschool Deaf children and offer a variety of services characteristic of a separate church. Clergy perform marriages and funerals for the Deaf constituency throughout the area and perhaps offer a vacation Bible school for people of all ages. The vacation Bible school may attract Deaf children and adults and is staffed by people from a wide geographic region.

The uniqueness of this model is that the Deaf congregation is one of the few in the country that exists within a very large hearing church and yet functions as a separate congregation. An additional benefit of this model is that it does not require mission funding outside the large-member local church.

### **Interpreted Ministries**

A variety of models exist within the category of interpreted ministries. The use of the term "interpreted" indicates that the Deaf ministry exists within a hearing congregation and that a sign language interpreter is used to make the worship service and other activities of the church community accessible for its Deaf members. Many churches begin by providing an interpreter for Sunday morning worship services and then work towards having separate worship services or even establishing a separate Deaf church. It is important to note that, while many United Methodist interpreted ministries exist within large hearing churches, some in very small rural churches are working out very well.

The most challenging aspect of interpreted ministries is making every part of the church's life accessible so that the gifts and skills that Deaf people bring can be fully utilized within the faith community. Interpreting only Sunday morning worship services usually does not allow this to happen. Consequently, some of these congregations use an interpreter for everything: worship services, religious education classes, committee meetings, and fellowship activities. The interpreter may sign for the Deaf members or use voice for the hearing members when a Deaf person is in a leadership position.

Other churches provide separate Bible studies or religious education classes for their Deaf members while using interpreters for everything else. They may also have a separate

fellowship group or even a Deaf council that plans activities for the Deaf constituency.

The number of Deaf members often dictates whether a church mainstreams them into existing Sunday school classes or whether it can provide separate religious education classes for Deaf children or Deaf adults. If there is a small number, they are often mainstreamed into a hearing class and an interpreter is provided to facilitate communication between the class members. Another model is to have a separate Deaf worship service once or twice a month, inviting the Deaf people to join the hearing congregation on the other Sundays.

If a pastor is fluent in sign language, he or she may choose to interpret parts or all of the worship service, committee meetings, Bible studies, etc. In other instances, the pastor may sign everything she says but not sign or interpret what other people are saying. The church will continue to use an interpreter for the lay leader or the comments of the other committee members or class members.

If pastors are learning sign language, they will often choose one portion of the worship service to sign and then have the interpreter do the rest. Usually they will sign a prayer or a call to worship or even a Scripture reading. Once they become more fluent, they may sign their sermons. While formal settings still utilize an interpreter to a large degree, at least informal conversation and visitation can occur with direct communication rather than through an interpreter.

Attempts by the pastor to learn sign language are greatly appreciated by the Deaf community, as are Deaf pastors themselves. In The United Methodist Church, the *Book of Discipline* requires that the pastor use the common language of the people in the parish to which she is appointed. Though the ratio of Deaf people to hearing people in an interpreted ministry might be small, pastors with Deaf members should still

make the effort to learn sign language.

Some United Methodist churches use an interpreter for worship services only. Others use an interpreter for every aspect of the life of the church. Some churches use interpreted ministries but have separate fellowship activities, religious education classes, and/or worship services. The United Methodist Church also has congregations whose worship services are shown on television. These include a sign language interpreter for viewers who are Deaf. The National Committee on Ministries with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People can provide resource contacts for these various types of ministries.

### **Religious Programs in State Residential Schools**

Unfortunately, some states have laws that prohibit religious education classes or services from being held in any state school. In those states, it is very difficult to provide religious education programs for Deaf children and youth. Not only are they not permitted to receive religious education after school during the week, but also, because they ride a bus back to school on Sundays, they usually don't receive any religious instruction in their home church, either.

Some schools that do not permit church groups to have activities on the school grounds do allow the children to be taken off campus to a local church after school for education classes, provided they have written permission from their parents. The school will even assist with transportation, but usually it is up to those providing the ministry to supply the transportation to and from the school. Insurance is always a big issue for ministries that operate in this fashion.

Many states do allow religious education classes and/or worship services to be held after school on an extracurricular basis, or a

particular state school might "look the other way" and bend the state laws to allow church groups to come on campus one day a week. Some school administrations are very cooperative while others can be outright hostile. It depends on who is in charge and what the individual's previous relationship to church organizations was.

A few rare schools actually have "chaplains" that minister to the student population. They usually work part-time and are supported by their denomination rather than by the school. Still, a chaplain has access to students in ways religious education classes can't begin to have.

The Illinois Great Rivers Conference has a ministry at the Illinois School for the Deaf. It offers three basic programs: religious education classes at a local church on Sunday mornings for five different age groups, midweek Bible study for older Deaf students (also at the church), and a confirmation class that meets on the school's campus during the week. The Deaf Ministry program provides the students with transportation between the school and the church.

The Baltimore-Washington Conference offers religious education classes for elementary and secondary students at two residential schools. The United Methodist Church also cooperates with other denominations providing religious education for ecumenical classes on special occasions and holidays.

For those state schools that do permit some kind of ministry to the students, parental permission is almost always required. A common procedure is for a United Methodist representative (usually a teacher or minister) to ask for a table at the school's orientation. Most schools offer a time at the beginning of the school year when the parents can come and receive information on the various aspects of the school. At this time, a representative can pass out flyers explaining the church's program, talk to par-

ents personally, and ask them to sign permission slips to allow their children to attend religious education classes, worship services, or other activities sponsored by the church. It is an excellent opportunity for a representative to meet the parents and get acquainted.

Often other denominations that offer religious education classes will also be present at the orientation. When that is the case, most parents choose which denomination's classes they want their child to attend. If their particular denomination does not offer classes, they might choose to send their children to a United Methodist class, even if their background is not United Methodist.

It is important for the representative to cultivate a good relationship with someone in authority at the school so that trust is developed and good rapport continues. One issue that arises is space. Most teachers don't want other teachers and students using their rooms after school. They want to know where everything is and that things will not be in disorder when they show up for work the next day. Often religious education classes have to make do with whatever space they are given, though it is not always ideal. It may be a huge gymnasium, a dining room, a section of the library, the teacher's lounge complete with soda machines, or with luck, a resource room. Either way, making the space "holy" and creating appropriate activities for that space is often very difficult. Transporting the children to a local church might be a better option if the space limitations at the school are too great.

### **Conference Models**

Many conferences have not yet undertaken ministries with their Deaf constituents. Other conferences support Deaf ministries, but as yet they have no conference staff to coordinate

them; the pastors and local Deaf churches stay knowledgeable about Deaf ministry within the conference. Most conferences that do have Deaf ministries, however, have some kind of conference staff person.

The Baltimore-Washington Conference, which has two Deaf churches, Gallaudet's campus ministry, and a few interpreted ministries, has a conference-wide Deaf Ministry Committee composed of pastors and sometimes lay representatives from the various Deaf ministries. It coordinates programs for the entire conference, such as summer camps for Deaf children, retreats for Deaf adults, and training workshops for religious interpreters. The conference has a line item in its yearly budget that is set aside for Deaf ministry. This money is used to supplement the three pastors' salaries, to fund conference-wide events, and to help additional local congregations establish new Deaf ministries.

The Illinois Great Rivers Conference also has a conference Director of Deaf/Hearing Impaired Ministries. It has a Board of Trustees that oversees the program, one-third of whom must be Deaf. The program is an official institution of the Health and Welfare Agency of the conference. The majority of the funding comes from a combination of monies budgeted by Health and Welfare, conference Advance Specials, direct service fees, and contributions.

Within the conference are interpreted Deaf ministries at different stages of development. Some interpret worship only once or twice a month but have separate Deaf fellowships. Others are fully interpreted, while still others have separate Bible studies, fellowship activities, and Sunday school classes. The ministry is responsible for giving guidance and assistance to churches that are providing or are interested in starting interpreted worship services and Bible study classes.



In addition to the interpreted ministries, the conference supports and administers Deaf/Hearing-Impaired Activity Centers where Deaf people can come for education, information, Bible study, problem solving, and general advocacy. The conference has district teams that assist in identifying helpful resources and people within their districts who can utilize the ministry. Another project under the guidance of a commissioned deaconess assists children and adults who have handicaps in addition to deafness; the focus is on training staff in the use of sign language, developing social activities, providing spiritual guidance, etc.

The North Indiana and South Indiana Conferences do not have official conference-wide models for handling Deaf ministry. However, they have formed a board that oversees all the Deaf camps in the two conferences. This board, constituted under the Conference Committee on Camps and Conferences, plans, coordinates, publicizes, and facilitates the three major Deaf camps that the conferences offer each year. The board itself is composed of Deaf and hearing people, camp counselors, parents of Deaf children, ministers, and the camp resident manager.

### Camps and Retreats

The feasibility of offering a summer camp ministry depends on the number of Deaf students in a particular age range and the availability of trained leaders and counselors to operate the camp. Yearly access to Deaf camps therefore varies, depending on the circumstances.

The North Indiana Conference (now joined by the South Indiana Conference) has the longest history of summer camps for Deaf children. Three Deaf camps are offered every year. Each has been in existence for a long time and

has developed quite a reputation. Counselors and campers come from all over the country to attend the camps, which are becoming known internationally as well.

One camp, which lasts one week, is geared specifically toward Deaf children aged 4 to 12. Counselors and staff are put through an intensive training program before the camp begins. The second camp is also a week long but focuses on Deaf youth aged 13 to 18. A conference bus called "God's Nightcrawler" transports the youth to various places throughout the country. They begin at the camp, travel overnight on the bus, and spend time together at an interesting place. The third camp is really a weekend that concentrates on the entire family. Organized by the Director of Deaf Ministry but run by Deaf adults, this camp welcomes Deaf families with hearing children and hearing parents with Deaf children. In addition to activities for children and adults, there are special intergenerational programs.

Unlike some of the other conference camps, these camps are open to Deaf children and youth from anywhere in the country. Counselors and staff are also accepted from places outside the conference.

The Baltimore-Washington Conference offers a week of summer camp for Deaf children that is sponsored by the Deaf churches in the conference. The camp advertises through the Deaf ministries within the conference as well as through the religious education programs in the state residential schools. An annual camp for deaf-blind adults is also offered.

The Illinois Great Rivers Conference offers a long weekend camp in the summer that is intergenerational. Deaf adults, youth, and children attend, along with any hearing family members who wish to come. The conference also offers two week-long signing institutes during the summer that are aimed at hearing people. One is for youth and the other is for

adults. These programs attempt to begin training people who may wish to become interpreters later on.

Some conferences offer retreats in lieu of camps. Contact the National Committee on Ministries with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People for more specific information about camps and retreats.

### **Campus Ministries**

The United Methodist Church is active in campus ministry programs at Gallaudet University in Washington, DC. Gallaudet has a part-time chaplain who works with the students in programming, Bible studies, and worship services. With a primary emphasis on counseling, this ministry is provided for staff, faculty, and students. Aside from this ministry, however, it has been difficult to make inroads onto college campuses. Some colleges do not have offices of campus ministries at all. There are many universities that have chaplains, but very few of them are knowledgeable about deafness or fluent in sign language.

## **CURRICULA AND RELIGIOUS EDUCATION**

There is always a need for good curricula for both Deaf children and Deaf adults. Because The United Methodist Church has concentrated on Deaf ministries with adults, there are a few educational materials suitable for work with adults. For work with Deaf children, The United Methodist Church does not at present have any published religious education curricula, although a few local Deaf ministries have been writing their own.

This section will describe the adult and children's curricula that are available in The United Methodist Church and will explain how

curricula can be adapted for use with Deaf adults and children.

### **United Methodist Deaf Children's Curriculum**

A United Methodist Visual Curriculum is being developed, and sample lessons are available on request. A few Deaf ministries in the country have created their own curricula, and they can be contacted through the Health and Welfare Ministries Unit of the General Board of Global Ministries for a preview or for help in preparing your own.

The Deaf ministry in the Illinois Great Rivers Conference has developed a children's curriculum. Those involved in this ministry may be able to provide information on how to adapt existing curricula as they have done.

In the Baltimore-Washington Conference, no written curriculum can be duplicated and passed out, but the pastors of the Deaf churches have had many years of experience in teaching Deaf children. While this curriculum is not available, the pastors can provide insights and guidelines on teaching both deaf-blind students and Deaf children.

In addition to the resources listed above, a small brochure of curriculum information was developed by the Committee on Ministry with People who are Deaf or Hearing-Impaired of the National Council of the Churches of Christ (NCCC). It is entitled "Christian Education Resources for Deaf People" and gives a brief overview of the various denominational resources and where to write to get more information. The Roman Catholic Church has also put together a packet of materials, which includes the publication from the NCCC Committee, called "Resources for Ministry with Deaf and Hard of Hearing Persons."

### **Guidelines for Adapting Existing Curricula for Deaf Adults**

When adapting existing curricula, make sure that the Deaf adults understand the religious vocabulary used. Most adult curricula are written for a community of faith and presume knowledge of the Bible—its characters and stories—which Deaf people do not always have. They may not have had any access to religious education while growing up and may not know the names of people and places in the Bible. Make sure that terms are defined in advance so that everyone has the basic knowledge needed to understand the lesson. When working with Deaf curricula, it is also helpful to use visuals—maps, charts, newsprint, overhead projectors, etc. The more visual you can make the lesson, the better.

Translating from one language to another can often be a frustrating experience. English is full of idioms that don't translate into American Sign Language or Signed English and vice versa. Be conscious of the language issue. If you are not fluent in both languages, find someone who is—preferably a Deaf person. Ask about possible translation or interpretation problems in the language and vocabulary used in the lesson.

Besides language, the most important adaptation regarding curricula has to do with the illustrations and stories used. If these stories come from the lives of those who are culturally hearing, they do not always relate to the Deaf students in the classroom. Replace such illustrations and stories with ones that come from the experiences of Deaf people living in the Deaf world. Deaf people prefer stories that relate to experiences they know firsthand.

Obviously, it's important to have a teacher who is fluent in the language of the Deaf members, whether that is American Sign Language or some form of Signed English. However,

when such a teacher isn't available, the Omega Project's "The Bible: ASL Translation" videotapes can be used (unfortunately, only a small portion of the ASL Bible is available to date). Those that are completed can be used to show a Scripture text to be discussed. The video can then be paused while a discussion takes place, after which additional verses can be shown. For information about Omega Project videos, check the Resources section on page 76 for contact information for Deaf Missions.

### **Guidelines for Adapting Existing Curricula for Deaf Children**

When working with any children, lessons must be made exciting, but with Deaf children, what is added to the lesson is of utmost importance. This means using drama, visuals, experiential learning—anything to keep the children's attention. Teachers who are not skilled signers should not depend on language, be it English or sign language. They should learn the lesson and memorize the basics of the Bible story, then act it out, mime it, or use flannel-graph images or metal board figures to tell the story. Just reading a story in English should be avoided, since it bores both the Deaf and the hearing children alike. The story needs to be told, not read. Being a good storyteller involves using body language and facial expressions to convey the mood and essence of the story. The body and face can communicate just as much as, if not more than, signing.

If the lesson includes a contemporary story or illustration about children's lives, make sure that it relates to Deaf children's lives as well. If not, then write a new story or invent an illustration that is based on the daily experiences of the Deaf children. Make the curriculum relevant to their lives.

When you introduce new vocabulary or a

new religious concept, make sure that the Deaf children learn the sign for it as well as seeing the printed English word. Biblical names and places and religious practices such as baptism and communion may all be new to them. Give them the signs as well as the English when defining these terms.

Most Deaf children enjoy dramatizing a story after the teacher has told it. They don't need scripts and will make up their own dialogue and action once they know the storyline. Therefore, it is crucial that the first telling of the story be clear.

When doing crafts as part of the lesson, keep in mind that activities such as finger-painting can be very messy, because Deaf children communicate with their hands. Paint or anything else handled by the children can end up everywhere. Come prepared with sponges and towels. If socialization and interaction with other students are goals, also remember that when Deaf children's hands are kept occupied with cutting and gluing and coloring, they can't easily communicate like hearing children, who can cut and paste while they are talking. In a mixed group of hearing and Deaf students, the Deaf students will tend to socialize less when their hands are occupied with craft activities. It might be wise to plan other types of activities that involve more joint interaction.

### **Creating Your Own Deaf Children's Curriculum**

The hardest aspect of creating your own curriculum is following a pattern or appropriate model for children's faith development. You might want to consult the themes, biblical texts, and development from existing curricula for help. Otherwise, many pick a Bible story and go from there. The United Methodist Congress of the Deaf Curriculum Committee

has developed sample lessons for children aged 4 to 12, using a Visual Curriculum approach with a series of sequential illustrations based on the New Testament. These are available as guides for developing your own lessons.

It is important to make the initial storytelling come to life in whatever way possible. Once the children know the story, they can act it out, make crafts that reinforce it, and even apply it to their own lives by telling similar stories from their own experiences.

Find a person with good sign language skills (preferably a Deaf person) or use a good interpreter in a mixed class. (Keep in mind, though, that the interpreter is only as good as the storytelling of the hearing teacher.) If the teacher has poor sign language skills, the message that comes across to the Deaf children can be very inaccurate. When situations like this cannot be avoided, supplemental aids must be used in conjunction with language. Visuals, drama, and other experiential methods of learning are extremely helpful.

Visual images must be consistent and sequential. Most children's curricula have a picture here and a picture there and the story is filled in with words. However, English is often the second language of Deaf children and they depend more on visual images than on written words. So create your own pictures or use flannelgraph images or metal board figures to tell the story visually.

As much as possible, let the visual images carry the story and fill them in with a little language rather than filling the written story in with a few pictures. If the teacher's signing skills are poor and the visuals are not strung together in a sensible order or leave major gaps in the story, the children often come away with a very skewed theology as well as a poor religious education.

The best scenario is to have Deaf teachers, or Deaf teachers working with hearing teachers, so that communication is smooth and accurate. This also provides role models for children.

## **LEGAL RIGHTS OF DEAF PEOPLE AND THE RESPONSE OF THE CHURCH<sup>6</sup>**

There are three laws that have a major impact on the rights of Deaf people: Section 504 of the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act (IDEA)—formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975—and the Americans with Disabilities Act (ADA) of 1990. As pastors often become advocates for their parishioners, it is important for them to have a basic understanding of these laws.

### **Section 504**

Section 504 of the Rehabilitation Act of 1973 requires all government offices and programs to be accessible. It also requires that hospitals, schools, and other institutions receiving more than \$2,500 in government funds be in compliance with Section 504 and therefore be accessible.

In Deaf ministry, this means that if a Deaf person has to go to the hospital, the hospital is responsible for providing a qualified interpreter to facilitate communication. Many hospitals don't obey this law and need a firm nudge from Deaf people, pastors, and other advocates within the community. The same applies to other community services such as Social Security, food stamps, social services, public assistance, sexual offense crisis centers, hotlines, health clinics—anything that receives government funds.

Section 504 also relates to seminaries that

receive monies through government student loans. If the check is sent directly to the seminary rather than to the student, the seminary is responsible for making its facilities and programs accessible. This may entail provision of sign language interpreters, oral interpreters, and/or notetakers, depending on the individual needs of the Deaf person.

### **Individuals with Disabilities Education Act (IDEA)**

IDEA states that children with disabilities have a right to an education within the "least restrictive environment." This has often been interpreted to mean that children with disabilities should be mainstreamed within their local school district rather than educated in a separate special school. While this concept is supported by most other disability groups, among the culturally deaf there is a perception that state residential Deaf schools provide a better education and a more welcoming environment for Deaf children than do local public schools.

For those who are Deaf, being mainstreamed often means being the only Deaf student in a hearing school instead of attending a school where one can participate in sports, drama, and social activities. The mainstreaming movement has caused many school districts to educate their Deaf students themselves rather than send them away to the state residential schools. Because of this, many residential schools are being closed for lack of enrollment.

The loss of residential schools causes much concern and grief in the Deaf community. If parents want their Deaf child to attend the state school for the Deaf, many advocates are needed to convince the local school authorities that the Deaf school is the "least restrictive environment" for that particular child.

<sup>6</sup> This resource, developed by the Health and Welfare Ministries Unit of the General Board of Global Ministries, is designed to provide local churches, annual conferences, general agencies, and church-related institutions with principles and guidelines regarding workplace policies on Deaf ministries. The information provided in this resource is for educational purposes only. Contact an attorney for specific legal advice.

## The Americans with Disabilities Act

At present, the Americans with Disabilities Act (ADA) of 1990 is the most important civil rights legislation for people with disabilities. Unlike Section 504, which deals primarily with government agencies and programs receiving government monies, the ADA covers the general public. This act deals with employment, transportation, public accommodations, telecommunications, and the responsibilities of state and local governments.

The ADA states that employers cannot discriminate against a person with a disability in hiring or promotion. Employers with 15 or more employees must also provide "reasonable accommodation" to enable people with disabilities to perform their jobs without structural or communication hindrances.

The transportation section requires that all new public transit buses be accessible. In addition, transit authorities must provide comparable paratransit to those individuals who cannot use conventional means. Trains must have at least one accessible car, and any new train cars must be accessible. All new bus and train stations must be accessible, and rapid, light, and commuter rail systems must be accessible. Amtrak stations are required to be accessible by July 2010.

Public accommodations and government facilities such as restaurants, hotels, retail stores, hospitals, and courts may not discriminate against people with disabilities. All new construction and renovations of facilities must be accessible. In existing facilities, physical barriers must be removed or an alternative entrance provided. Among the construction and service requirements are visual fire alarms (with flashing lights), TTYs, amplified tele-

phones, *assistive listening* systems, sign language interpreting, and CART [computer-aided realtime translation], unless these would prove to be an "undue burden" on the business establishment. The question here is always: "What is an undue burden?"

The telecommunications section requires all telephone companies that serve the general public to offer a telephone-relay service to individuals who use TTYs or TDDs. In addition, immediately after the passage of the ADA, a Television Decoder Circuitry Act was passed that requires television manufacturers to include a decoder chip in all televisions 13 inches or larger built after July 1, 1993. This allows anyone to access the closed captions without a decoder machine.

The one disappointing feature of the ADA is that it exempts religious organizations from compliance with physical accessibility requirements. In effect, it says that restaurants, hotels, and every other public facility must be accessible—but not churches. Therefore, it is imperative that, out of a Christian moral and ethical stance, churches volunteer to follow the guidelines of the Americans with Disabilities Act even though they are not required to do so by law. Congregations can take the lead in making churches accessible and assist in educating the community as its businesses and local establishments make plans to comply with this law.

For updated information about the Americans with Disabilities Act and its impact within the Deaf community, write to:

NAD Law Center  
814 Thayer Avenue  
Silver Spring, MD 20910-4500

# Ministry With Late-Deafened and Hard of Hearing People

## INTRODUCTION

Part Two deals with those who are *hard of hearing*<sup>1</sup>, *late-deafened*, or *oral deaf* and prefer to associate with the *hearing* world. It's difficult to know how many people are hard of hearing, because the denial stage of acknowledging a hearing loss averages seven years. The most recent studies show that approximately 28 million people (ten percent of the population) have some degree of hearing loss. Of that 28 million, 26 million are hard of hearing and 2 million are deaf. (The term "deaf" refers to *audiological deafness* in these statistics.) Only about one-fourth of the 2 million deaf people were born deaf or became deaf *prelingually* (before speech acquisition), which means that approximately 1.5 million are late-deafened. (An increasing number of late-deafened people are getting a *cochlear implant*, whose electrodes stimulate the auditory nerve according to signals received from an externally worn speech processor, often enabling users to function as hard of hearing.)

Although most prelingually deaf people communicate in *American Sign Language* (ASL), a small percentage are oral deaf. They communicate primarily by speech and *speechreading* and consider English (or another spoken language) their first language. Much of the information contained in this section also applies to oral deaf people.

The hard of hearing population of 26 million is subdivided into a small percentage that

was born hard of hearing or became hard of hearing before the age of 18 and a large percentage that became hard of hearing in adulthood. For those who were born or grew up hard of hearing, coping skills and adaptations to the hearing world were acquired in childhood. Depending on the degree of hearing loss, it is possible for these children to learn throughout childhood how to make their way in the hearing world despite their hearing loss. Nevertheless, the passage into adulthood for children and youth who are hard of hearing will not be easy when it comes to effective communication; learning to speak clearly can be a major challenge, requiring extensive speech therapy.

In contrast, the general coping skills learned by those who grew up with normal hearing may not be sufficient to deal with a hearing loss that occurs in adulthood. New coping strategies must be learned and adaptations must be made. Hearing loss in adulthood requires a variety of changes in people's lives as well as in the lives of those around them.

## The Culturally Hearing

The cultural orientation of those who are late-deafened or hard of hearing is that of the *hearing* culture. They grew up hearing. Their first language is English or the spoken language of their family (Spanish, Korean, etc.). They went to public schools, and if they married, they married hearing people. They have

<sup>1</sup> Terms that are defined in the Glossary on page 83 are italicized on their first appearance in the Introduction and in each Part.

lived all of their lives in a world oriented toward sound. Some of these people have never met a Deaf person in their lives. They have no sense of the existence of the *culturally deaf* community or understanding of signed languages.

Those who identify themselves as oral deaf would also consider themselves *culturally hearing*. While audiologically they are deaf, they do not know the language of Deaf people, nor do they adhere to the values and modes of behavior that culturally deaf people believe in. Although they grew up deaf, they were conditioned to belong to the hearing world from the very beginning of their deafness. They wore hearing aids, learned to speak and speechread the English (or another) language, and consider themselves part of the hearing world. Some may have developed sign language skills, but this is primarily to communicate with Deaf people. Oral deaf people communicate primarily through speechreading, the printed word, and any technological aids that may prove useful. They may prefer to use *oral interpreters* for meetings and church services.

Most late-deafened and hard of hearing people have little contact with the Deaf world and do not learn sign language. Most would like to continue to function in the hearing world as much as possible in spite of their hearing loss. They need access to means that make spoken language visible (such as captioning) or audible (such as *assistive listening equipment*). Because those in the *Deaf community* also experience an audiological hearing loss, late-deafened and hard of hearing people may feel a kinship with them. However, late-deafened and hard of hearing people primarily consider their hearing loss from a medical or audiological perspective, and they are usually not familiar with the cultural/community aspects of

deafness. If they are aware of their local Deaf community, many of them do not wish to associate with it or to be identified as "deaf."

It should be noted that *deaf-blind* people generally identify with either the Deaf or the hearing worlds depending on whether they became deaf before or after the acquisition of spoken language. Deaf-blind people who were born deaf or became deaf prelingually often become proficient in *tactile communication* (signing or finger-spelling into the hands), and those who were born blind or lost their sight early usually learn to read Braille. Most deaf-blindness occurs in adults, and this population forms a varied group, depending on the progression and degree of loss. More information about deaf-blindness is provided in Part Three of this manual.

### Between Two Worlds

In some ways, being late-deafened or hard of hearing is like being between two worlds. A few will cope well, learn new ways of being, and try to fit into both worlds. Most, however, will feel a sense of "falling through the cracks" or being "without a culture." While they grew up in the hearing community, their hearing loss does not allow them the easy flow of communication that occurs within the world of sound. When family and friends tell stories and jokes, late-deafened or hard of hearing people often feel lost. They may ask others to repeat what was said, but if they do, they may feel as if they are imposing or interrupting the flow of conversation and may receive insensitive responses such as "It's not important" or "I'll tell you later" or the dreaded "Never mind."

At the same time, hard of hearing and late-deafened people are generally not part of the culturally deaf community, because they are seldom fluent in the language of that culture (American Sign Language in the U.S.). Nor are



they familiar with the values, modes of behavior, or folklore of Deaf culture, and while they now need to depend more on visual cues, they are still *culturally hearing* and think in sounds rather than in images. If they have no skills in sign language, they will probably feel rejected in dealings with Deaf people. If they learn to sign, they can find a place in the Deaf community, but major changes are required to become fully bicultural. And bicultural is a key word here. The late-deafened or hard of hearing person may no longer feel "hearing," but years of living as a hearing individual are integral to the person they are becoming. Most late-deafened or hard of hearing individuals who learn sign language use a form of Signed English rather than ASL, because English is their first language.

Caught between the Deaf and hearing cultures, hard of hearing, late-deafened, and many deaf-blind people experience an overwhelming feeling of loss, isolation, and alienation that can lead to depression and/or withdrawal from church and society. Holly Elliott's story illustrates the difficulty that many have in accepting their hearing loss and building a new identity. She is an author and a retired counselor-therapist who was on the clinical staff of the Center on Deafness located at the University of California at San Francisco (UCSF). She was also coordinator of the Independent Living Skills Language Lab at San Francisco State University and is a past president of the United Methodist Congress of the Deaf and a winner of the Association of Late-Deafened Adults' prestigious I. King Jordan Award for her contributions to the field of deafness. Holly has forged a new identity despite "hearing people [who] think I am hearing because my speech is good and Deaf people [who] think I am hearing because I am not fluent in American Sign Language."

## "From Denial to Acceptance"<sup>2</sup>

The most difficult road for hard of hearing and deafened people to travel is the road from denial to acceptance. Even the word "acceptance" is difficult for a person who has experienced normal hearing. More realistic terms might be "adjustment" and "acknowledgment." Unless deafness occurs suddenly, hearing impairment creeps up on you. Denial is all too often the result. We see it when we install *assistive listening systems* in churches. Most people do not want to use equipment that labels them "hearing impaired."

I went through that experience for many years. I became deaf when I was a junior in college, majoring in music. Over a period of two weeks, I lost the ability to hear the upper half of the piano keyboard. I could hear the lower half just fine; the upper half was gone. People were not speaking clearly—they were mumbling. I thought it was their problem, not mine. I went to see an *audiologist* who told me that I was severely deaf, it would probably become worse, a hearing aid would not help me, and I would just have to learn to live with it.

So I spent the next 25 years trying to pass as a hearing person. The normal hearing in the low frequencies and my skill at lipreading were very helpful. I even directed a church choir for 14 years. I knew if the sopranos were off pitch by the expression on the tenor's faces. But after my husband died in 1968, even the low pitches began to go. I had never allowed myself to experience grief and I paid dearly for those repressed feelings. I had the feeling that deafness was my problem and nobody else's. The turning point came when my pastor said: "Why don't you stop fighting deafness and start using it?"

An enormous change occurred when I

<sup>2</sup> "From Denial to Acceptance" by Holly Elliott was published in the *ALDA News*, Summer 2000. "Culture Shock upon a Rooftop in Monaco" (which appears within the body of her story) was originally published in the *Deaf American Monograph*, 1994. Both are reprinted with permission.

could honestly say three words: "I am deaf." It was a time when there was a lot of interest in training a deaf person to become a professional in the field of counseling. A rehabilitation counselor for the deaf encouraged graduate training in rehabilitation counseling, and I was the only deaf person in the rehab counseling program at Sacramento State University. New York University was interested in training a deaf person as well, and they accepted me into their Ph.D. program. I did my fieldwork for the masters in counseling at the University of California's San Francisco Center on Deafness. The director, Hilde Schlesinger, was interested in training a deaf person to become a therapist, so they offered me a job on the clinical staff. I had a choice to make: NYU or UCSF? I chose to start working with Dr. Schlesinger at UCSF, where I stayed for ten years, doing play therapy with deaf children and counseling their hearing parents.

It was a whole new world. I really had to work at learning sign language, and it helped to take a two-week European tour with a Deaf group. That was a profound experience in the difference between a culturally deaf person and a "culturally hearing" deaf person. I had a decision to make: do I immerse myself in ASL and become part of Deaf culture? Or do I hang onto my hearing friends and family and cross over between the two cultures?

### **Culture Shock upon a Rooftop in Monaco**

Cultures meet reflectively upon a rooftop in Monaco  
And clash.

I am deaf—not deaf; hearing—not hearing.

I talk to hearing, I am deaf.

I talk to deaf and I am hearing.

I talk to French, I am American.

Part of all, yet all of none.

I talk, I sign to Mary Alice.

She does not comprehend my signs  
But writes and writes and studies French  
And takes the train alone to Nice.  
And yet, she finds her own reality.  
She scatters notes in French  
And takes the train alone to Nice.

Last night we walked and found ourselves  
Amongst a crowd at the casino  
Pressed against a fence.  
Flora signed, "You ask them what they're waiting  
for.  
Please—you can talk."

"Pardon," I said (in French), "Pourquoi?"  
And pointed to the waiting crowd.  
"Elle est arrivee, la Princesse Grace!"  
(And more) but, "Je ne comprend pas," I said.  
I translate and the hands and fingers fly  
In great excitement.  
"I do not understand.  
You sign too fast!"

I rage upon the rooftop in Monaco.  
Not deaf, not hearing  
Mary Alice studies French  
And passes notes in French.  
I study signs and pass my signs

To patient, understanding friends.  
Do we attempt to be what we are not?  
Or are we searching for ourselves,

For new dimensions of ourselves?  
And will our common schizophrenia  
Add self-fulfilling struggle  
To the search for self?

Culture shock upon a rooftop in Monaco.  
My deaf friends join me on the roof.  
We sign together in the summer sun.  
And take each other's pictures  
Against the backdrop of the Cote d'Azure.

My choice was not acceptance, but  
acknowledgment. I continued my interest in  
music by organizing and directing a sign lan-

guage choir in the Methodist church where I helped start a Deaf ministry. I have become increasingly aware that the needs of a "culturally hearing" deaf person are different from the needs of a culturally deaf person. But I like to think I can communicate with both.

Or at least I could until my vision started going. Now a deaf-blind friend is urging me to go all the way and become part of the deaf-blind community. But I am not willing to go that way. Is it denial again? Perhaps. A cochlear implant has improved my ability to hear but I'm not about to give up sign language, although I don't have the occasion to use it very much in the retirement community where I now reside. There are a lot of people where I live who are denying their hearing loss. So you know what I'm doing? I'm teaching a sign language class! It's Signed English, because we need to talk and sign at the same time.

Continuing Care Retirement Communities are a godsend for the aging, providing apartments of various sizes, dining room services, healthcare, support for independent living, all sorts of activities, and a warm extended family. I have participated in various exercise programs, have organized sign language classes, and demonstrated technology (cochlear implants, large-print computer programs, and a reading machine) to other residents with similar needs.

Don't wait for your church to become accessible; take the initiative yourself. Our two churches, Temple United Methodist in San Francisco and Fremont United Methodist in Portland have both responded to my need for CAN (computer-assisted notetaking). The congregation at Fremont raised the money for a digital projector, and one can read the service on a large screen to the left of the pulpit. Every Saturday I get an e-mail of the complete Sunday

service that I can read in advance on my reading machine. And I am in choir directing again! I work with the children for a signing-singing session just before Sunday school starts on Sunday mornings. The connection with The United Methodist Church also opened up activity with United Methodist Congress of the Deaf.

I asked a contemporary friend the other day: "When do you become aged?" Her response was immediate: "Tomorrow." Hmm. Is denial a factor here, too? Not if it allows you to "live it up" despite your age!

## MULTIPLE DISABILITIES

When involving a person with hearing loss and one or more additional disabilities, care should be taken to communicate well to find out this person's particular needs and gifts that can be shared. Oftentimes hearing loss is seen as a secondary disability, as somehow not as significant, and it can be overlooked in providing appropriate access.

### "Don't Overlook My Hearing Loss!"<sup>3</sup>

My name is Mary Jones. No, this is not my real name, but my story is real. I was born with cerebral palsy and hearing loss. My mother noticed I had hearing loss as a small child, but the doctors did not listen to her concerns. Instead, they told my mother that my cerebral palsy was enough for her to deal with. For ten years, my mother kept quiet about my hearing loss until the evidence was so strong that my doctors agreed with her and I was finally given hearing aids.

I attended a special education class when I started school. The class had a mixture of students—some were slow learners, some had mental challenges, others had a variety of physical handicaps. I had a difficult time learn-

<sup>3</sup> Mary Jones (not her real name) has graciously agreed to share her story. She is hard of hearing and also has cerebral palsy.

ing in these classes, as I was the only one who had a hearing loss. People were always making fun of me or calling me names because I could not hear. Junior high school was especially difficult. I became so depressed that the school counselor sent me to a state mental facility for an evaluation. I was there for a few months. My mother applied to a different high school, and, after I visited the school for several interviews, they accepted me.

At this new school, I met for the first time other students who had a hearing loss. These students, however, signed and did not speak. I wanted to learn sign language but had few opportunities to learn signs; so I found myself in class with signing students whom I couldn't understand and hearing students and a teacher who spoke whom I could only partly understand. I remember playing the part of the mother in a play. Some of the kids were using their voices and some were signing; it was all confusing for me.

I was able to get a job before I graduated from high school. I worked in a library for ten years. During that time I started to learn sign language. My parents were not happy about it, but I had always wanted to learn. I was in my late twenties and determined to stay with it until I could sign and understand sign.

I began attending a Deaf church while continuing to attend my home church, which was composed entirely of hearing people. The pastor at the Deaf church encouraged me to join. I attended regularly and slowly began to understand what was going on. I joined the deaf choir and enjoyed traveling with the members on concert tours. I told the choir members I would not speak with my voice while I was with them; I would only sign. This helped me continue improving my sign language skills.

Sign language helped me understand what I was missing when listening and lipreading.

Later I got a new job working in an office. My boss wanted me to answer the phone, but I told her I had only a limited ability to use the phone and could not hear well enough to speak with strangers easily. She felt that because I could talk, I could answer the phone. I had to get assistance from some friends to explain the situation to the head manager and resolve the problem. I am learning to help people understand about my hearing loss.

I have had problems communicating with my family as well. The hardest part was when my mother passed away. My father called to let me know that my mother was going to die at any minute. She had been battling cancer for eight years. I called my friend and the two of us went to the nursing home where she was getting hospice care. When my friend, who was also an *interpreter*, arrived, my brother insisted that my friend leave. He said that only family members should be at mother's side at the time of her death. No strangers were allowed. I said I needed my friend there so she could sign to me what was going on. No one in my family could sign. But my brother would not hear of this. He told my friend she had to leave.

I was left alone with a hearing family who were all talking and I was missing everything that was going on. I was very hurt, but I did not say a word. Mom died around midnight, and I saw the nurse talking to the family. I did not hear what she said but I figured that Mom had just died because everyone started to cry.

For the funeral service, I insisted upon having an interpreter, and the family agreed. I felt peace for the first time in many years and was able to understand what was said at my mother's funeral.

## COMMUNICATION ISSUES

Communication occurs in two directions: sending and receiving. People send out information through speech, body language, sign language, and so forth. These are known as *communication modes*. When traditional modes of sending and receiving are no longer available, alternative modes of communication must be used.

The communication modes of those who are oral deaf, late-deafened, and hard of hearing vary to some degree. For the majority of these people, speechreading will be a crucial way of receiving information. Most have understandable speech and will continue to communicate their thoughts orally, but they must find additional methods to receive information. As hearing decreases, however, it becomes more and more difficult for people to monitor their own speech. Eventually those who are late-deafened may need speech therapy or find alternative ways to send as well as receive information.

Speechreading is used by almost all oral deaf, late-deafened, and hard of hearing people in varying degrees. Only about 30 percent of spoken English is visible on the lips, and some sounds look the same as others—it's not possible to speechread the difference between "baste" and "paste," "fast" and "vast," or "trip" and "drip." Therefore, those who are hard of hearing use a combination of *residual hearing* (enhanced by a hearing aid or some other technological device) and speechreading. Those who are late-deafened may learn a form of Signed English to supplement what they miss in speechreading.

People's speechreading abilities vary; some are highly skilled, while others are unable to acquire the knack. Speechreading is much harder if one has no residual hearing. In addition, some people are easier to speechread than others, and speechreading becomes more diffi-

cult as the distance from the speaker increases and the lighting decreases. Many late-deafened and hard of hearing people find that the speaker's skill in communication and speaking clearly make a big difference in the ease with which they can understand the conversation.

*Cued speech* is a visual communication system that uses handshapes near the mouth to aid in speechreading. In the U.S., eight handshapes represent consonant sounds, and they are performed in four different locations around the face to represent the accompanying vowel sounds. Cued speech can make visible the 70 percent of the English language that is invisible on the lips. The system takes much less time to learn than sign language, but there is a scarcity of people who know the system and fewer still who are trained to cue speech.

Oral interpreters are most often requested by oral deaf people, but some late-deafened and hard of hearing people also prefer this mode of communication. Oral interpreters mouth the words being spoken and use interpreting techniques they have learned to ensure that the full message is conveyed.

Some late-deafened people may request a sign language interpreter. Interpreters signing for late-deafened people usually sign in English word order (*transliteration*) while mouthing the words so they can easily be speechread.

In addition to speechreading and sign language, other communication aids are available, such as assistive listening systems and devices, *computer-assisted notetaking (CAN)*, *CART*, *C-Print*, *graphic notetaking*, and writing. A properly fitted hearing aid can assist a hard of hearing person with communication. Late-deafened people benefit from cochlear implants and *auditory brainstem implants (ABIs)*, surgically installed devices that restore sound in varying

degrees by bypassing the damaged auditory areas. Unlike glasses, hearing aids and implants don't restore normal functioning, but they can effect a major improvement in hearing ability. Hearing aids, implants, assistive listening equipment, CAN, CART, and C-Print are covered in detail in the section entitled "Technological Aids" below. Graphic notetaking and the use of print material are covered in the section on "Accessibility Issues in the Life of the Church," page 52.

It is important to find out from late-deafened or hard of hearing people which methods of communication they prefer. Some are excellent speechreaders and others depend heavily on sign language interpreters. Many know no sign language and rely on their residual hearing and technological aids. Most of those raised in a family whose first spoken language was English communicate well in written English.

### Communication Tips

The League for the Hard of Hearing's advocates offer the following suggestions for communicating with people who have a hearing loss:

- Get the person's attention first!
- Face the person—have the light on your face.
- Speak up, but do not shout.
- Speak slowly and clearly—don't overemphasize.
- Cut out background noise by turning off the TV or radio.
- Don't hide your mouth with your hand or an object.
- Rephrase rather than repeat a misunderstood sentence.

- Write important information to be sure it's understood.
- Have the person repeat vital facts to be sure they are correct.

### "Growing Up Hard of Hearing"<sup>4</sup>

I was born in 1945, and my short stay at the hospital turned into a fight for my life. I was the only infant to survive an epidemic of infectious diarrhea that spread throughout the hospital nursery room, and was known as the "Miracle Baby" by hospital staff. I was saved by a cocktail of medications that were given in larger quantities than usual for a baby, however, and for a much longer period of time than normal.

The doctors told my parents they expected side effects, but they were unsure what these side effects might be. The main repercussion from the treatment ended up being hearing loss. My mother noticed I was not responding to sounds in the same way as my older sister did when she was a baby. My hearing loss became "official" when I was between 18 and 24 months old.

I started school at the age of three at Atwater School, a public school in a suburb of Milwaukee, Wisconsin. I was placed in a special classroom for deaf and hard of hearing children. When the time came for kindergarten, I was integrated into the regular classroom, attending a separate language development session a couple of times a week. Fortunately, the children at this school were used to deaf and hard of hearing children. We all had some classes together, such as art, physical education, and even, in some cases, music. Most of us in the deaf and hard of hearing classroom were good at sports, so we were usually among the first picked by the hearing kids for team sports. We were well accepted

<sup>4</sup> Ginny Clark-Wright is the author of this account. She has been hard of hearing since infancy, having a loss of 70 dB in the right ear and no residual hearing in the left ear. She has worn a hearing aid since age four. A teacher, she has also been the Arizona State Coordinator for Self Help for Hard of Hearing People (SHHH) for many years. She serves on the Arizona Commission of the Deaf and Hard of Hearing and is an officer with the United Methodist Congress of the Deaf.

by the hearing children, which eliminated much of the cruelty that some children display towards those who are different.

All this changed when I began second grade at a private school. The students had no experience with hearing loss and were so different in their attitude of "who they were," even at so young an age. I tried hard to adapt, but found the experience quite jarring, becoming more self-conscious and wary. My parents transferred me back to Atwater School after only one semester, and once again I felt at home. I remained there in the regular classes from third through fifth grade.

At the beginning of sixth grade, I transferred to my regular hometown school, and that transition went quite well. As I was walking up the stairway that first day at the new school, I was politely reminded to tell my sixth grade teacher of my hearing loss and to sit in the front row. I cringed at the thought. What was the point of making an issue of it right at the start? When the time was right, I would tell my teacher, I decided. As to where to sit, that was easy. I picked the third seat in the third row. I could hear the people speak from the back of the room better at that location and use my lipreading skills and residual hearing to catch what the teacher and others in the front said.

I didn't want to mention my hearing loss for another reason. So much was happening very fast, and I wanted to get a better feel of my new surroundings. Pride and ego got involved. The classmates were nice, but the way they rattled off their names so quickly made me realize I wasn't going to be able to "bluff" my way for very long, especially with background noise. My instincts told me these students were not accustomed to being around hard of hearing people, not like my classmates at the previous school. I wasn't ashamed of being hard of hear-

ing, but I wanted to show others that hearing loss was not going to stand in my way and that I could handle anything if given the chance. I resented the thought of being treated differently.

Once I felt comfortable, my teacher learned my "secret." I think she knew it all along. She was a caring teacher, and knew just how to deal with me. Soon I was making friends and enjoying my new school.

Even to this day, I hear from people about the positive and negative sides of mainstreaming and of the importance of the teacher's attitude in dealing with a child who has a disability. Based on my observations over the years, much of the success of these interactions has to do with the amount of exposure or contact a teacher has had with people with disabilities during her lifetime. Teachers in the regular grades should be required to take special education courses to help sensitize them to the variety of disabilities they may encounter during their careers.

I am pleased today to see the tremendous advances that have occurred with technological aids. The general openness toward technology, with people comfortably wearing headsets while walking, should help reduce the stigma of wearing hearing aids or using assistive listening devices to help one hear. Though I was mainstreamed, my adjustments back in the '40s and '50s were minimal. I did wear a body hearing aid, a bulky affair strapped to my body. With the use of the hearing aid, lipreading skills, and residual hearing, I managed pretty well.

One challenge for a hard of hearing child is to imitate the sounds in language correctly. Not being able to hear the high-frequency sounds (such as *s*, *th*, *sh*, and *ch*), made me more curious about the English language; I would peer closely at people to observe what they were saying. I have trouble pronouncing the "s"

sound. Yet, when people are lipreading me, they can "see" my "s" just fine. It helps to have a sense of humor about the many possibilities to mishear and misunderstand things.

I became a good notetaker beginning in the sixth grade, a skill that stayed with me through my college years. Notetaking was a challenge, especially since I did not have Superman's x-ray eyes and could not lipread what the teacher was saying when she spoke while writing on the blackboard. I began to scribble rapidly, coming up with my own version of shorthand. The only problem was that it would take a long time to remember and figure out my shorthand once I was safe at home! A notetaker service would have been helpful back then, especially during high school and college. These are services that are now provided in schools, along with oral interpreters or sign language interpreters.

Entering college was a time of growing freedom and expansion for me. Part of this was growing up; part was graduating from the body aid to a behind-the-ear hearing aid. I felt better and looked better.

I have often been asked if being hard of hearing affected my career choices. In some ways, yes. I realized some areas in which I was interested would be inviting more stress than I wished to deal with. I have enjoyed a long career in teaching, however, and have found it rewarding work.

My parents, sister, and grandparents are to be given much credit for being instrumental during my formative years. They provided me with such positive influences, instilled a sense of humor in me, and did their best to guide me toward independence. It was a way to prepare me for life's challenges along with. Their love and support helped me face the future and be well adjusted. I thank them for that.

## TECHNOLOGICAL AIDS

Equipment used by Deaf people is discussed in Part One: Deaf Ministry. These devices can benefit late-deafened and many hard of hearing people. Consult pages 10-11 for information on TTYs, the telephone relay service, and TV *closed captioning*; visual fire alarms and other alerting devices are covered as well. Also note that the church telephone and any public telephones in the church should be equipped with volume control for those who are hard of hearing.

Many hard of hearing and late-deafened people wear hearing aids, cochlear implants, or auditory brainstem implants. The technological aids most beneficial to churches are assistive listening systems, personal assistive listening devices, and computer-assisted notetaking. These and other aids are discussed below.

### Hearing Aids

Hearing aids come in all shapes and sizes, with implantable hearing aids now a possibility. A hearing aid can enable the wearer to hear soft sounds that were previously inaudible and can selectively amplify missing frequencies, such as high-pitched sounds. In church services, it can help significantly in picking up more of the speaker's voice, but it cannot restore normal hearing. Hearing aids do not cure distortion of sound, which can hinder speech discrimination. They are less helpful for more severe hearing losses, which are usually accompanied by significantly decreased speech discrimination ability (such individuals may be candidates for a cochlear implant). They are also less effective in picking up speech from a distance, in the presence of background noise, and in bare rooms where sounds tend to echo. They can, however, help people make the best



of what hearing they have. Those that come equipped with a *telecoil* (also called a *T-switch*) can be used in conjunction with an assistive listening system to enable the user to hear the worship service with much more clarity.

### Cochlear Implants

The cochlear implant (CI) is an electronic device that can partially restore hearing to people with sensorineural (inner ear) hearing loss who cannot understand speech with a hearing aid. The surgeon inserts an electrode array into the cochlea of one ear. After healing, the patient is hooked up to an external speech processor in the form of a small body-worn or behind-the-ear device. A microphone behind the ear receives sound and sends it to the speech processor, which changes it into a code that is sent to a transmitter on the scalp. The transmitter then sends the signal through the skin to a receiver/stimulator that converts the code to electrical signals. These signals are sent to the electrode array inside the cochlea, which stimulates neurons to send messages along the auditory nerve to the brain. At the central auditory system in the brain, the signals are interpreted as sound.

The restored sound is not the same as normal hearing, and implantees have varying degrees of success. Some are able to hear well enough to use a regular telephone, though communication in noisy situations is still difficult. Music is quite complex and doesn't translate very well, but nevertheless many CI users find they enjoy listening to it again. Cochlear implants can be used with the assistive listening systems and devices described below by attaching a patch cord from the speech processor to the receiver or by activating the telecoil (T-switch) in implants equipped with one (telecoil users also need a *neckloop* and receiver for

FM and infrared assistive listening systems).

### Auditory Brainstem Implants

Auditory brainstem implants (ABI) go even further. They are placed directly on the auditory brainstem, bypassing the ear and the auditory nerve, and are used by those who no longer have a functioning auditory nerve. Individuals with NF-2, or *neurofibromatosis type 2*, develop benign tumors on the auditory nerve, and surgical removal of the tumor can sever or destroy this nerve. ABIs have not reached the same levels of success as cochlear implants, but they are proving to be of benefit in restoring a sense of environmental sound.

### Assistive Listening Systems

Hearing aids don't deliver speech clearly from a distance or in the presence of reverberation (which is common in sanctuaries and other large, bare rooms) or background noise. Fortunately, these problems can be overcome by assistive listening systems, which deliver sound directly from the microphone to the person's ear, hearing aid, or cochlear implant. For large-room listening situations (such as a worship service), there are basically three types of assistive listening systems: the FM system, the infrared system, and the induction loop system (also referred to as audio loop or teleloop). Each has the same purpose—to get the best quality sound directly from the sender into the receiver's ear without any distortion or background noise. The Resources list at the end of this manual (page 74) includes some manufacturers and distributors of assistive listening systems.

#### The FM System

The *FM system* is basically a very small radio station that transmits sound via radio

waves. There are narrow-band and wide-band frequencies that have been reserved for purposes such as this. For large areas, a transmitter is plugged into the sound system. When there is no sound system, the speaker can wear a portable pager-like transmitter and microphone. The hard of hearing person uses an FM receiver, which is attached to earpieces worn in the ears or to headphones worn over the ears. Some hard of hearing people have hearing aids with a telecoil (T-switch); they can plug a neckloop into the FM receiver and then turn on their hearing aid's telecoil switch instead of wearing an earpiece or headphones (cochlear implant wearers generally use a patch cord they themselves provide instead of a neckloop).

The following are some things to keep in mind about FM systems:

- The radio signal can be transmitted through walls; this means that the sanctuary system and a classroom or meeting room system cannot operate at the same time, since users will pick up both signals. (FM systems are available that allow for use of different frequencies in this type of situation.)
- The systems are portable and can be used where needed, including events held out doors or off the church premises.
- Each person must have an individual FM receiver and an earpiece (or, if the receiver is used with a telecoil-equipped hearing aid, a neckloop).
- Because the receiver is visible, some hard of hearing people may refuse to use it.
- The cost of the system depends on how many receivers are needed.
- Someone must make sure that receiver batteries are charged.
- The sound quality is excellent.
- Problems can arise in areas where there are a lot of radio or TV stations whose signals might cause interference. If you are not sure, have someone come to your church and test the radio signals to see if there is a free band that you can use. Then request that band when ordering your transmitter and receivers.

### *The Infrared System*

This assistive listening system transmits sound via invisible infrared light waves. The transmitters (emitters) can be installed on the walls or placed on top of tripods. Depending on the size of the room, the church may need to purchase several emitters so the room is covered with infrared light. The light waves carry a signal to a "bubble" on the receivers. One-piece infrared headphones or under-the-chin headsets may lack the jacks needed for those who have hearing aids with telecoils (T-switches) to attach a neckloop, so infrared receivers with jacks should also be provided. (Cochlear implant wearers use a patch cord instead of a neckloop.) The following are pointers to keep in mind about the infrared system:

- The light waves cannot be transmitted through walls, which means that two separate systems can operate at the same time, but separate emitters will be needed for each room.
- Infrared transmission cannot be used out doors, because it requires walls to reflect the light waves back into the space where the sound will be received.
- Each person must have an individual infrared receiver (for use with hearing aid telecoils {T-switches}, a neckloop and an infrared receiver with a jack are needed).
- Because the receiver is visible, some hard of

hearing people may refuse to use it.

- The cost of the system depends on how many individuals need a receiver and how many emitters are needed to cover the room with infrared light waves.
- Someone must make sure that receiver batteries are charged.
- There must be enough emitters to make sure there are no "holes" in the room. Some parts of the room may be better than others. The best reception occurs in a direct line from the light wave.
- The sound quality is very good, as long as the room is covered with infrared light.

### *The Induction Loop System*

The *induction loop system* transmits sound through an *electromagnetic field* created by induction loop wire placed around the room. It requires an amplifier, an induction loop, and telecoils as receivers. The loop wire is placed on the floor, under a rug, around the walls, or even in the ceiling. It then plugs into the amplifier along with the microphone. The main benefit of this system is that people with telecoil-equipped hearing aids can use it by simply turning on their T-switch—no separate receiver is necessary. Unfortunately, only 30 percent of hearing aids sold in the U.S. have telecoils, and receivers are needed for everyone else.

- Sound can "spill over" and can go through walls, ceilings, and floors. Care must be taken that two systems do not operate simultaneously in rooms that adjoin either horizontally or vertically.
- Costs for installation in a large area such as a sanctuary can be high.
- It's possible to loop one section of a room (such as the first few rows of a sanctuary); users must sit within the looped area to

receive the signal. If this arrangement is chosen, make sure that the looped area is in the front (to enable speechreading), accessible to wheelchairs, and indicated in publicity. It's preferable to loop the entire room.

- Induction loop receivers are needed for those who do not have hearing aids or whose hearing aids do not have telecoils (T-switches).
- Someone must make sure that receiver batteries are charged.
- There may be "holes" in the room, depending on the shape of the electromagnetic field and the position of the telecoil in the hearing aid or receiver. Sometimes tilting the head or moving around will improve reception.
- The sound quality is very good as long as one is well positioned in the electromagnetic field.

### *Conference Microphones*

For meetings, a *conference microphone* can be used.

Conference microphones are designed to be used in conjunction with an FM or infrared assistive listening system. One type is a box that sits in the center of the table, where its multidirectional microphone picks up everyone's voice and sends the output (via a transmitter) to the hard of hearing person's receiver. Conversation flows more easily because the microphone does not have to be passed from one person to another. However, speakers will not be picked up clearly if they are too far away. Another company manufactures small triangular conference microphones that can be "daisy-chained" together and placed in different locations on the table to provide better coverage.

The wire loop of small portable induction loop assistive listening systems can be taped around a table for a meeting and used in con-

junction with a microphone that can be passed around as needed. In addition, one company manufactures a portable tabletop infrared emitter (transmitter) that comes with four microphones, which can be placed in various locations around the table.

### Publicizing an Assistive Listening System

Make sure that the assistive listening system is well publicized and that ushers are trained to help those who can benefit from it. Place a sign in the vestibule announcing "ASSISTIVE LISTENING SYSTEM AVAILABLE—PLEASE ASK," accompanied by the assistive listening system symbol:



The church newsletter should include articles about the system when it is installed so that people can become familiar with it and will feel encouraged to try it. On a weekly basis, a short line at the top of the worship bulletin will serve to inform new members and visitors of its existence. Some churches prefer to inform people by including a short statement at the end of the bulletin with the announcements, but this method can cause people to sit through an entire worship service without knowing that the church has an assistive listening system, only finding out afterwards when they read the announcements at home. Consider including a line right after the church's name and date before the order of worship: "Our church is equipped with an (FM, infrared, induction loop) assistive listening system. Consult an usher for assistance." Just before worship begins, it's help-

ful for the pastor or worship leader to announce the system's availability and where to obtain receivers. (However, this is not a substitute for written notices, since hard of hearing people may not hear the announcement.)

The availability of the assistive listening system should also be mentioned in all church newspaper ads, yellow pages listings, websites, and other publicity. The First United Methodist Church of Pensacola, Florida, announces the availability of its "hearing assistance system" on the church website's home page, which provides a link to a detailed explanation of its FM system at: [www.pensacolafirstchurch.com/hearing\\_assistance.htm](http://www.pensacolafirstchurch.com/hearing_assistance.htm)

### Personal Assistive Listening Devices

The systems described above are intended for use in large rooms. They are referred to as wireless because they don't use connections between the transmitter and receiver. Instead, the sound is transmitted through the air by alternative methods. Pager-sized wireless FM transmitters can be used for one-on-one communication, and there are also inexpensive *hard-wired* devices such as *Pocketalkers*<sup>TM</sup> that can be used for one-on-one communication between people who are in proximity. These personal devices are very helpful for pastoral counseling and one-on-one visitation.

Hardwired personal assistive listening devices have transmitters with microphones for which the hard of hearing person carries a receiver and wears some form of earpiece or (when used with a telecoil-equipped hearing aid) a neckloop. Hardwired and wireless personal assistive listening devices are also available for use with television, enabling a hard of hearing person to increase the volume without making it louder for the other members of the family. Likewise, telephone amplifiers are available with adjustable volume controls;

those with normal hearing can set the amplification at zero.

### Computer-Assisted Notetaking

Computer-assisted notetaking is a technological process that permits instant or "real-time" captioning through the use of a laptop or desktop computer equipped with a word processing program. An additional benefit is that the entire proceedings can be printed out for those who cannot take notes while keeping their eyes on the displayed words. In small-group settings, the computer's video monitor may be all that is required to display the typed words so that late-deafened and hard of hearing people can read them.

In large group settings, however, additional projection equipment is needed: an overhead projector, a *liquid crystal display* (LCD) unit, and a movie/slide screen. The LCD unit must be one designed for this purpose. It requires special cables and a special program that allows the computer monitor to transfer the image to the LCD. The computer is plugged into the LCD unit, which sits on top of an overhead projector. The printed words go through the computer into the LCD. The overhead projector then projects the words onto the large movie/slide screen. The more distance there is between the large screen and the overhead projector, the larger the letters will be. It is helpful to have software that can create large-print font styles on the screen, since the projector can display only what appears on the computer monitor.

The organization Self Help for Hard of Hearing People has developed guidelines for computer-assisted notetakers. They provide insights concerning the best way to type the conversation. Included are helpful hints such as:

- Type the name of the speaker before the comment is typed.

- Double or triple space so that notes are easier to read.
- Space down a few lines when the topic of conversation changes so that people can follow more easily.

It is often impossible for the notetaker to type everything that is said word for word. Efficiency is improved if prewritten materials such as liturgies, Scripture, hymns, anthems, prayers, sermons, agendas, and outlines are entered as files in the computer in advance and scrolled for viewing at the proper time. The notetaker should pack as much information as possible into a brief summary. It is helpful if the entire group understands the process of computer-assisted notetaking and follows some basic guidelines of its own, such as talking one at a time. (When people talk over each other, it is impossible to type both conversations simultaneously.) It is also helpful to have people identify themselves before they speak, especially if the notetaker is unfamiliar with the group.

### CART and C-Print

The process of computer-assisted notetaking is similar in many ways to those of realtime court reporting (computer-aided realtime translation, or CART) and C-Print. CART reporters use a stenotype machine to provide an almost word-for-word rendition of the spoken presentation on a computer monitor, TV, or screen, while C-Print captionists type with abbreviation software to produce a condensed version on a laptop computer. C-Print was developed by the National Technical Institute of the Deaf primarily for classroom notetaking but is also being used for business, community, and church meetings (*Typewell* is a similar transcription system using different abbreviation software). For some meetings of late-deafened

and hard of hearing people, court reporters have been known to volunteer their services. If volunteers cannot be found within the church, an alternative would be to hire local court reporters or C-Print captionists.

With the increasing number of people who are hard of hearing as well as the increasing number of people who have computers, investment in an LCD and/or overhead projector may be a good way to make meetings, conferences, and workshops accessible to those who are late-deafened or hard of hearing. (Note that culturally deaf people whose primary language is American Sign Language may not understand computer-assisted notetaking and other computer transcription methods, since users need to be fluent in English.)

#### **Resources on Assistive Listening Systems**

Self Help for Hard of Hearing People (SHHH) carries a variety of books, videos, and articles related to assistive listening systems and other assistive devices, such as *Assistive Devices: Doorways to Independence* (video and book), as well as a list of assistive listening system manufacturers. The League for the Hard of Hearing also sells publications and videos about assistive listening systems and devices, including *Communication Access for Persons with Hearing Loss* (book) and *Come Hear with Me* (video). Contact information for both organizations is provided in the Resources listing under "Organizations That Offer Resources" on page 80.

#### **Resources on Computer-Assisted Notetaking and C-Print**

Self Help for Hard of Hearing People carries the video *Computer-Assisted Notetaking (CAN): Now You See It—Visual Technologies for Deaf and Hard of Hearing People*, as well as literature about CAN. See "Organizations That Offer Resources"

(page 80) in the Hard of Hearing and Late-Deafened Resources section of the Resources listing for contact information.

Samples of C-Print text and training materials and other information about C-Print can be obtained from:

Northeast Technical Assistance Center  
Rochester Institute of Technology  
National Technical Institute for the Deaf  
52 Lomb Memorial Drive  
Rochester, NY 14623-5604  
Telephone: 716-475-6433  
E-mail: netac@rit.edu

### **MODELS OF MINISTRY WITH LATE-DEAFENED AND HARD OF HEARING PEOPLE**

While both late-deafened and hard of hearing people are committed to living within the hearing world and share common problems with accessibility, their needs are very different. Those who are hard of hearing try to utilize whatever residual hearing they have, while those who are late-deafened have virtually no usable hearing and must depend on other means of communication. Despite the differences, however, all of them have spoken language as their first language.

In terms of ministry, these populations prefer a "hearing" worship service to separate ministries and worship services geared specifically for a deaf, late-deafened, or hard of hearing group. They have probably had religious education and church experiences and are "comfortable" with the hearing style of worship. They are mainly seeking better access to that which has been meaningful and familiar to them. Therefore, the task of the church is to find

ways to become more accessible to these populations. It should also be kept in mind that many hard of hearing people are ashamed of their hearing loss and need encouragement to accept assistance.

It is statistically probable that almost every church in the country has hard of hearing people in its membership because of the aging population, yet models of ministry with this group in The United Methodist Church are few and far between.

Some conferences that have Deaf ministries serve both those who are culturally deaf and those who are late-deafened and know sign language. In recent years, the United Methodist Congress of the Deaf has also begun to deal with the issues of nonsigning hard of hearing and late-deafened people, but much work still needs to be done in this area.

The models that currently exist are based on three aspects of ministry: use of technological aids, printed communication aids, and support groups. A church that is sincere in its desire to serve the late-deafened and hard of hearing constituency would do well to consider all three.

### Use of Technological Aids

The technological aids used by local churches vary. The most common is some type of assistive listening system in the sanctuary. Some of these systems are very outdated; others are in need of repair, while still others sit dormant because no one knows how to use them.

In addition to large-room listening systems, personal assistive listening devices or personal FM systems can be used for one-on-one communication. These are very effective for nursing home visitation or visiting those who are homebound and hard of hearing. Those who have hearing aids with telecoils (T-switches)

can plug a neckloop into the device instead of using headphones or earbuds.

Personal assistive listening devices can also make small classroom or meeting settings more accessible. Each person who wishes to say something takes the device's microphone and speaks into it. The microphone doesn't amplify the sound for all, but rather sends amplified sound directly into the hard of hearing person's receiver. Having to pass the microphone around is a disadvantage of this system, but it can also be an advantage because it makes it impossible for more than one person to talk at a time and it gives the hard of hearing person time to locate the speaker for the purpose of speechreading.

One problem is that hearing people are not always consistent in making sure that they have the microphone before beginning to speak. As an alternative, a small group can use a multidirectional conference microphone that sits in the center of the group.

An additional large-room listening system may need to be installed in a room other than the sanctuary. If the sanctuary has an FM system, it can be easily transported to another location, making it unnecessary to have an additional system.

### Use of Printed Aids

"Printed aids" refers to all the means by which the late-deafened or hard of hearing person can receive information through the printed word. The method may be as simple as carrying a pad and pen for writing messages, or it may involve printing as much as possible in the bulletin so that the late-deafened or hard of hearing person can read what is being said. This is particularly helpful for choir anthems, which are difficult to speechread or understand through an assistive listening system. The pas-

tor may be able to provide printed copies of the sermon as well.

Other printed aids include group methods such as graphic notetaking and computer-assisted notetaking. While graphic notetaking is cheaper, computer-assisted notetaking is more detailed (one can type many more words per minute on a computer than one can write on newsprint). Another benefit of having a computer is that it can immediately print out a record of the minutes of the meeting.

### Hosting Support Groups

A few churches have taken the initiative to offer support groups for people who are late-deafened or hard of hearing. More churches, however, are providing space where some of the existing secular organizations can meet. Self Help for Hard of Hearing People (SHHH) has chapters all over the country, and many meet in churches. *The Association of Late-Deafened Adults* (ALDA) is also growing and beginning to have chapters around the country that meet in church buildings. Unfortunately, the church members are not always aware of community programs or ministries that meet in the church on weekdays. If SHHH or ALDA groups are holding meetings in a church, they should be well promoted and advertised through the church bulletin or newsletter so that the late-deafened and hard of hearing members within the congregation will take advantage of them. For the location of local SHHH and ALDA chapters, check the Resources section (page 80) for information about contacting these organizations.

## ACCESSIBILITY ISSUES IN THE LIFE OF THE CHURCH

Because communication is involved in every aspect of the church's life and ministry, access to

worship should be complemented by access to educational programming, fellowship activities, and administrative meetings. Churches that provide only access to the worship service through some type of assistive listening system miss out on the gifts and skills that late-deafened and hard of hearing people can bring to a community of faith. Consult the Accessibility Audit on page 93 for a detailed survey that can be used for evaluating and upgrading auditory and visual communication.

Many hard of hearing and late-deafened people need to keep their heads up and eyes open in order to speechread. It's important for the pastor or worship leader to inform them that the custom of bowing the head and closing the eyes for prayer is not mentioned in the Bible or in the *Book of Discipline of The United Methodist Church*. Before prayers, the congregation should be invited to assume an "attitude of prayer," and it can be added that bowing heads and closing eyes are optional. When a hard of hearing or late-deafened person is present in a small group, be sure to remind participants to keep their heads up when praying aloud so their mouths will be visible. Good lighting is likewise essential for speechreading.

### Worship Access

The two most common forms of access to worship services are some type of assistive listening system and the printed word.

Many churches ask for prayer requests from the congregation during the worship service. If this happens, it is helpful to provide a wireless microphone that can be passed around so that everyone can hear the joys and concerns of the people (although those who depend on speechreading may not be able to follow). If there is no portable microphone, the



pastor or prayer leader should repeat or summarize what was said so that those who are dependent on the sound system, the assistive listening system, and/or speechreading can understand the prayer request.

The bulletin usually contains the corporate prayers, responsive readings, calls to worship, etc. The hymnbook provides the lyrics, and pew Bibles give people an opportunity to read the Scripture texts if they cannot hear them clearly enough. Announcements too are usually printed in the bulletin. This type of access is common in most churches. Beyond it, however, consideration should be given to printing the words to the choir anthems. Also, while everything cannot be printed, some late-deafened and hard of hearing people like to have access to a copy of the sermon manuscript or outline. Most prefer to read it after the service to fill in what they might have missed, but some like to look it over before the service so that they can anticipate words and concepts that they will be listening for and speechreading.

As more and more late-deafened and hard of hearing people begin to assert their right to accessible worship, there may be a call for reserved seating in the front for those who depend on speechreading. Those who are still in denial about their hearing loss will probably not use it. Others may sit up close without knowing exactly why. They think they "hear" better up front when in reality they may already be speechreading.

For those who speechread the worship leaders, the faces of all liturgists should be well lit and not hidden by the pulpit, lectern, microphone, or pulpit lamp. If the speaker is short, consider providing a small portable "box" or riser so that his or her mouth won't be hidden by the lectern or pulpit.

Another means of access to worship for those

whose primary communication mode is speechreading is an oral interpreter. Oral interpreters place themselves in proximity to those needing their services. The distance and angle often make it very difficult to speechread a minister standing in the pulpit, and only 30 percent of English words can be seen on the lips. By *lip-synching* (mouthing without voice) an easy-to-speechread rendition of what is said in the service, oral interpreters enable the late-deafened and hard of hearing attendees to speechread someone closer to them than the pulpit and make speechreading feasible in large room settings. However, it must be remembered that there are many late-deafened and hard of hearing people who are poor speechreaders and cannot benefit from oral interpreting. An oral interpreter is also unsuitable for hard of hearing people who need to combine speechreading with their residual hearing.

For those who use sign language interpreters, the interpreter is usually positioned in the front, or to the side, of the sanctuary. Late-deafened people who use sign language interpreters often also speechread the interpreter and may request signs in English word order (transliteration). The interpreter may need to use clear lip movements and to sign more slowly and clearly to be understood.

### Educational Access

Educational access will vary depending on the kinds of hearing loss, communication modes, and needs of the late-deafened or hard of hearing constituents. A portable assistive listening system may be usable in an educational setting. If the class is small enough, a conference microphone might be appropriate. Graphic notetaking will help provide visual clues. The use of computer-assisted notetaking is also a possibility. For those who depend pri-

marily on speechreading, the easiest solution might be to have a volunteer oral interpreter.

If the teacher does most of the talking, speechreading the teacher may be all that is necessary. If there is a class discussion, seating people in a semicircle may make speechreading possible as long as the class is small. If the class is too large or this approach is not effective, having one consistent person to watch is helpful. The late-deafened or hard of hearing people should be offered the chance to choose between a volunteer oral interpreter and a paid professional on the basis of which one they can speechread more easily. Family members should not be expected to provide this service. A trained pool of oral interpreters could be developed among members of the congregation, and the late-deafened and hard of hearing people could choose the ones they find easiest to speechread.

If videotapes are used for religious education, it is desirable to search for those that are closed-captioned and to use a TV capable of displaying the captions. All TV sets larger than 13" that were manufactured after 1993 have a built-in caption decoder, which can be activated according to the manufacturer's directions, usually by accessing the menu with the remote control.

### **Fellowship Access**

Social activities can be frustrating for many late-deafened and hard of hearing people. Unlike the quiet atmosphere of the sanctuary, a social meeting is usually characterized by a lot of background noise. When children are running around, chairs are being moved, and many people are talking at the same time, understanding a conversation can be very difficult. Hearing aids amplify the background noise as well as the spoken words, which may cause the noise level

to become nerve-wracking. For this reason, some may choose not to participate in fellowship activities. A Pocketalker™ or other one-on-one communicator may enable a hard of hearing person to communicate more effectively in a noisy social setting.

For programs that have speakers, set up a portable assistive listening system, use a graphic notetaker or computer-assisted notetaker, or provide an oral interpreter. For potlucks, picnics, and activities where there are no formal programs, it is often helpful to set up a few tables in a quiet corner of the room, away from the kitchen, out of the main flow of traffic, and remote from where children are playing. This will minimize the background noise and may allow the hard of hearing people to use their residual hearing to understand conversation directed toward them. Make sure there is enough room for their family and friends to sit with them. Don't reserve a table just for hard of hearing people, because they consider themselves part of the hearing community.

### **Administrative Access**

For committee meetings and board meetings, it is easy to provide either graphic notetaking or computer-assisted notetaking. Someone is already taking the notes or minutes of the meeting, and if this is done by computer, it can benefit the late-deafened and hard of hearing people as well as provide a record of the meeting that can be immediately printed out. If graphic notetaking is used, the secretary can type the official minutes from the newsprint or butcher paper sheets.

If the church does not have access to a computer and is not comfortable with graphic notetaking, provide an oral interpreter for those who rely on speechreading, and use a portable assistive listening system or conference micro-

phone for those who are hard of hearing. Remember that only what is spoken into the microphone (or near a conference microphone) will be transmitted to the hard of hearing person. A microphone can be passed around as needed, or the speaker can repeat comments and questions into it. If attendees are comfortable doing so, they should come to the front to speak into the microphone; this will also enable the hard of hearing person to speechread them.

Be open to the needs of late-deafened and hard of hearing people and let them know that it is not a bother to make things accessible for them. Young people with disabilities will often push for accessibility much more than people over 65 who are experiencing the effects of aging and don't want to be a burden to anyone. Withdrawal from situations where they can't follow conversation is often more comfortable than asking someone to make adjustments for them. Make it clear that they are valuable members and should remain active, because the church community appreciates what they have to offer.

Keep in mind, however, that many late-deafened and hard of hearing adults don't know what technological devices or other accessibility aids are available. They may not know exactly what to use because they don't always know what their choices are. Learn about them together. Explore the various ways all areas of the church can become accessible. There are materials available to help you on this journey. Check the Resources section (page 80) for contact information on the League for the Hard of Hearing and Self Help for Hard of Hearing People (SHHH).

## **EDUCATION, COUNSELING, AND ADVOCACY ISSUES**

Education, patience, and understanding are crucial to a ministry with hard of hearing and late-deafened people. Only a quarter of people who could benefit from hearing aids use them. Studies show that an average of seven years passes before people recognize the fact that they are losing their hearing and need to do something about it. For some, an accident or a tumor might create sudden hearing loss. For others, hearing loss may be the aftereffect of a disease or certain medications. But for most, the loss is gradual and progressive, frequently as a result of years of exposure to noise. A gradual loss is much easier to deny than a sudden one.

During the denial stage, the problem is often more acutely felt by family, friends, and coworkers than by the person whose hearing is diminishing. Miscommunications may occur that cause problems at home or at the workplace. The hard of hearing person may constantly tell others to "speak up and stop mumbling." Family and coworkers may be constantly asked to repeat things. Tensions and problems may build. Hard of hearing people may not be aware of missing important information or may bluff their way through the conversation, pretending to know what was said when they really don't.

Some people who are becoming hard of hearing will withdraw from church activities for no apparent reason. Others will tend to monopolize the conversation for fear that if they stop talking, they will become lost. By controlling the conversation, they will know what the topic is and will feel more comfortable.

Hearing loss is a very trying experience both for the person who is experiencing it and for friends and family members. Communi-

cation does not flow easily any longer. Attention must be given to an appropriate environment for conversation as well as the rate and pronunciation of speech. Calling someone from another room is often fruitless and contributes to misunderstandings. For many couples, the frustration and responsibility are too great and divorce occurs.

For those who are still denying their loss, there may not be much a pastor and church family can do, but they can be supportive of the other family members and provide educational experiences that may encourage the hard of hearing person to seek help sooner. An important way the pastor can provide support is to discuss hearing loss issues with the congregation on Disability Awareness Sunday, which is observed annually on a date determined by the annual conference (as indicated in the *Book of Discipline of The United Methodist Church*).

Hard of hearing people are often unaware of how much they can benefit from an assistive listening system, and many are reluctant to wear a receiver that is noticeable to others in the congregation. Favorable reports by congregants using the church's assistive listening system may encourage others to try it. Publicizing the system well and placing a sign in the vestibule not only help to spread awareness of its availability but also send the message that "it's okay to have a hearing loss and okay to accept help for it."

Occasionally a hard of hearing person or someone who is becoming deaf may talk with the pastor or a confidant at the church about the frustrations of hearing loss. However, because so many live in denial of their hearing problem, it is most often the case that a family member, coworker, or friend of the hard of hearing person will approach the pastor first to raise concerns. Here are some typical comments that may alert the pastor to a hearing loss.

- "Sally is withdrawing."
- "John is monopolizing the conversation in Bible study class."
- "Rita forgot to show up for an important meeting."
- "Joe acted on wrong information."
- "Margaret misunderstands everything."
- "Henry keeps the TV turned up so loud!"

Hearing loss is not the same for every person. Some may hear low tones but miss the high ones (this is the most common pattern). Others may hear high tones but miss the low ones. Still others may hear highs and lows but have hearing loss in the middle frequency range where most speech sounds occur. Not only is hearing loss different for different people, it's also inconsistent in the same person.

Hearing can fluctuate depending on the time of day, the situation, and the environment. A hard of hearing person may hear pretty well in a quiet room in a one-on-one conversation. The same person may have great difficulty hearing in the same room after a long day at work, or if he or she is sick, depressed, or taking certain medications. If there is a lot of background noise or if there is reverberation (common in rooms without carpeting or drapes to absorb sound), people have greater difficulty in using their residual hearing. Family members may say, "She hears when she wants to hear," when in reality she does hear better on some occasions than others; it is not a matter of choice.

Ministry with hard of hearing and late-deafened people requires an understanding of hearing loss and a sensitivity to the issues of both the person experiencing the loss and the family members. Simply encouraging the counselee to vent emotions may provide catharsis. The pastor's study may be a safer place to deal with anger and rage than the home.

The pastor, however, may begin to feel the same frustrations as other friends. Communication is slow and difficult. Miscommunication is common, and one finds oneself repeating things constantly. The pastor may become resentful over the amount of time it requires to provide basic support counseling and referrals while seeming to make little headway. She may find it easier to avoid hard of hearing people than to make an effort to visit them and take the time necessary to be an advocate for them. Other pastors may go overboard in trying to help and in the end foster dependency rather than enable the person to become a self-advocate.

It is very helpful for the pastor to have a personal assistive listening device, such as a Pocketalker™, for use in visitations and counseling sessions. This can reduce frustration for both the pastor and the hard of hearing person as well as provide a model for better communication at home or at work.

By becoming familiar with the diagnostic and other services provided by audiologists in the local area and learning a few of their names, the pastor may feel more prepared to counsel parishioners who are losing their hearing. Starting a support group or providing space in the church for SHHH or ALDA chapter meetings can also benefit newly hard of hearing and late-deafened people greatly. Here they can receive information, learn different methods of coping, and network with people like themselves so they do not have to feel alone.

Few people without hearing loss can truly understand the many emotions of a person struggling with acknowledging this loss. Grief is a natural process that must be worked through. Other losses follow: easy conversation, jokes, and humor; pleasure from music and voices; and nuances of shared intimacies

less likely to be repeated. One grieves these losses in one way or another.

When hearing loss is suspected, emotions range from anger and depression to feelings of fear, isolation, and self-doubt. Once acknowledgement has occurred, the hard of hearing or late-deafened person must then deal with doctors, technological equipment, new information, and different methods of communicating. Trying to communicate can itself be extremely draining and frustrating. In addition, there are many other aspects of life that need to be relearned or adapted to, all complicated by relationship tensions caused by difficulties with communication. The fatigue can become overwhelming. Some may withdraw, others may be irritable, and still others may exhibit rage at no one in particular. The sooner the hearing loss can be detected and acknowledged, the sooner adjustments can be made.

Denial can function in both positive and negative ways. It can be a coping strategy that allows the hard of hearing person to continue a "normal" existence and believe that there is nothing "wrong." On the other hand, it contributes to tensions in relationships and slows down the process of adaptation and moving on with one's life.

Denial and fear are understandable emotions. Hearing loss can turn a person's life totally upside down. The greater one's loss, the greater the changes that have to occur. Some will lose their jobs and need to go through a job-retraining program to learn new skills. Others may continue to work for the same company but in a different capacity.

Communication problems can develop with spouses and children. Little children can't understand why a hard of hearing or late-deafened parent seems to be ignoring them, when in fact the parent doesn't even know the chil-

dren are talking. Children soon realize that it is easier to talk to the hearing parent, and this contributes to the isolation already felt by the hard of hearing or late-deafened person.

The prominence of hearing loss in people over 65 (one-third of whom are affected) creates additional advocacy and counseling needs. When hearing loss is part of the aging process, many factors and issues become intertwined. *Presbycusis*, the most common form of hearing loss in older people, often involves a greater loss in the higher frequencies, leading to the inability to distinguish consonants, which are high-pitched. This results in speech discrimination problems as well as general hearing loss.

Those who develop a hearing loss due to aging may also be experiencing a decrease in other functions such as eyesight and mobility. Such people are more apt to withdraw or be passive about hearing loss. They accept not understanding others' speech as a normal part of life and do not assert their right to access. Retirement may already have caused them to feel "left out" of the mainstream of activity. Family and friends may attribute their lack of attention or forgetfulness to "old age" rather than recognize a hearing problem.

More and more people are experiencing hearing loss earlier in life, and awareness about the rights of people with disabilities in general is increasing. People will begin to recognize signs of hearing loss earlier, and the stigma surrounding it may diminish. Eventually those with hearing loss will learn to adapt and will want to remain as active as possible in their later years. The church will then have to deal with people who assert their right to participate in the life of communities of faith. We are

already beginning to see this occur as people become involved with self-help groups such as Self Help for Hard of Hearing People (SHHH) and the Association of Late-Deafened Adults (ALDA). The more they network with other individuals with hearing loss and learn about their options to remain active, the more they will request access to our churches.

### Advocating for Access

The *Americans with Disabilities Act* (ADA) and various other laws protect the civil rights of people with disabilities, including those who are Deaf, late-deafened, hard of hearing, and deaf-blind. Part One provides a helpful summary of the ADA in its concluding section on legal rights on page 34.

Late-deafened and hard of hearing people need to be made aware that the ADA requires provision of auxiliary aids and services that are necessary to accomplish "effective communication," such as sign language interpreting, CART (realtime captioning), or an assistive listening system. Many late-deafened and hard of hearing people mistakenly believe that they are entitled only to sign language interpreting, even if they cannot understand it, because this form of access has been the subject of most of the publicity and ADA lawsuits. Some public accommodations and government facilities display signs indicating that deaf and hard of hearing people have the right to a sign language interpreter, with no mention of any other forms of communication access. The church can help to increase the availability of appropriate access for nonsigners by informing them of their rights and advocating on their behalf whenever such access is not being provided.

### **Resources on Counseling and Advocacy Issues**

The Association of Late-Deafened Adults (ALDA) is an organization that networks with those who have become deaf. It publishes a newsletter, sponsors conferences, and has chapters in various places throughout the country that provide support and social activities. The ALDA newsletter has many helpful information columns as well as personal stories. This organization has truly been a godsend to many late-deafened adults. Contact information is provided in the Resources section at the end of this manual (page 80).

Self Help for Hard of Hearing People (SHHH) is an organization that focuses on those who are hard of hearing. It has been in existence for over 20 years and has chapters in most states. It publishes a magazine that has self-help infor-

mation and personal stories. It keeps its readers informed about recent technology and accessibility issues. It too sponsors national conferences, and the local chapters function as support groups and educational resources. SHHH has a variety of resources that are available for hard of hearing individuals and their family members, including pamphlets and videotapes on communication tips. Check the Resources section for contact information.

SHHH publishes a catalog (available from its website) that lists and describes its resources, including books, articles, videos, and other materials. Some books and videos are listed in the Resources section.

Two bimonthly magazines, Hearing Loss (published by SHHH) and Hearing Health contain valuable information relevant to hard of hearing and late-deafened needs. Check the Resources section for contact information.

## In Solidarity with Deaf-Blind People

The foundational premise of this book is that God calls the body of Christ to stand in solidarity with people who are *Deaf*,<sup>1</sup> *late-deafened*, *hard of hearing*, or *deaf-blind*.<sup>2</sup> Hearing loss is not a homogenous condition covered by one diagnosis and prescription. Deaf and late-deafened people share the inability to hear and understand sound, but they may not understand each other's culture and mode of communication. Hard of hearing people preponderantly do not consider themselves deaf, and they employ varied audio and visual aids for communication in the hearing culture. And "deaf-blind," as we shall see, is an umbrella term covering a wide spectrum of losses of hearing and sight and calling for yet other means of discourse appropriate to life in either the Deaf or hearing culture.

Nevertheless, the goal remains to achieve a spirit of solidarity among the disparate groups of people living with hearing and hearing loss that will lead to the removal of auditory and visual barriers to full participation in society. It is especially true for the church calling Jesus its Lord.

The apostle Paul offers a model. Lkening the church to a human body, he notes that no

one part exists alone; neither may the body be complete or effective without a variety of parts. No single part can insist that all the others be and act like itself. Each is essential to the well-being of the whole body (1 Corinthians 12).

The church must learn to respect and appreciate deaf-blind people, engaging them in the church's total life and work.

### WHO ARE DEAF-BLIND PEOPLE?

The adjective "deaf-blind" covers the conditions of being deaf and blind, deaf and partly blind (low vision), hard of hearing and blind, or hard of hearing and partly blind (low vision).

According to the *Helen Keller National Center* (HKNC),<sup>3</sup> mandated by the federal government to locate and register deaf-blind people for statistical and research purposes, there are about one million deaf-blind people in the United States.<sup>4</sup> This figure is formulated from existing studies and not based on actual registrations of deaf-blind people. The very fact that "deaf-blind" includes the four above-named subgroups, with variations of loss within each, makes it difficult to

<sup>1</sup> Terms that are defined in the Glossary on page 83 are italicized on their first appearance in the Introduction and in each Part.

<sup>2</sup> There are different spellings for "deaf-blind." Some select "deaf/blind," "deafblind," "Deaf-Blind," or (to denote members of the Deaf culture) "Deaf-blind." For our purposes in this book, "deaf-blind" has been chosen.

<sup>3</sup> The Helen Keller National Center is an excellent source of information and support services for deaf-blind people and those who associate with them. There are regional branches of this agency throughout the United States. Contact information is found in the Resources section, page 81.

<sup>4</sup> A figure of 983,000 deaf-blind people as of 2002 was determined by the Helen Keller National Center and stated in an e-mail to the author from Dorothy Walt, director of the Northwest regional office of HKNC. A formula of 346/100,000 times the national population was developed in a study of all definitions of sight plus hearing loss, and this formula was used to derive the current figure. The relevant study is cited in the following report: Wolf, E.G., Delk, M.T., and Schein, J.D. *Needs Assessment of Services to Deaf-Blind Individuals*. Silver Spring, MD: Rehabilitation and Educ. Exp. Inc., 1110 Fidler Lane, 1982.



acquire an accurate count; not all people living with the two sensory losses understand themselves to be "deaf-blind" people, thus remaining unregistered by HKNC.

The one million figure is not in addition to the 28 million people estimated to be Deaf, late-deafened, or hard of hearing. Deaf-blind people are counted within those three groups according to the nature of their hearing loss.

There are four categories of deaf-blindness based on the age of onset of each condition, according to the Rev. Dr. Peggy Johnson, pastor of Christ United Methodist Church of the Deaf in Baltimore, Maryland. Dr. Johnson has done extensive research into deaf-blindness and the church's response to the condition. She identifies the categories as (1) deaf and blind from birth, (2) deaf first, blind later in life, (3) blind first, deaf later in life, and (4) deaf and blind later in life. Agencies such as the *Usher Syndrome* project at the National Research Hospital in Boys Town, Nebraska, and the Helen Keller National Center divide the groups further by including categories of partial and progressing loss of hearing and sight.

There is no single cause of deaf-blindness. The condition may be genetic, as is the case with Usher Syndrome Types 1, 2, and 3.<sup>5</sup> Nongenetic causes include injury and illness, such as *meningitis*. The story of Helen Keller is familiar to many, due to the popularity of the stage play, *The Miracle Worker*. Illness robbed her of sight and hearing when she was 19 months old.

The largest single group of deaf-blind people comprises those who lost hearing and sight later in life. This number will grow, with life expectancy in the U.S. increasing to 77 years at the beginning of the 21st century (it was 47 in 1901).

Churches will thus encounter more older people who are becoming hard of hearing or deaf and living with low vision or actual blindness.

The loss of sight in older adults can be due to diabetes, glaucoma, unsuccessful cataract removal and lens implantation, diseases of the cornea, or age-related *macular degeneration* (AMD). The latter—a damaging of the macula located in the center of the retina (with a sparing of side vision)—is becoming the single largest cause of blindness in older adults. Functionally, AMD is the reverse of *retinitis pigmentosa* (RP), which first affects peripheral (side) vision (however, unlike RP, AMD does not cause total loss of sight).

## IS THERE A "DEAF-BLIND CULTURE"?

Is there a "deaf-blind culture" in the same way that there is a definable Deaf culture? The question is the subject of strong debate among deaf-blind folk, some arguing that there is such a culture, others disagreeing.<sup>6</sup>

Deaf-blind people who use tactile ASL (a form of *tactile communication*) as their primary language could be considered a subgroup under the Deaf culture. Those whose hearing loss developed later in life are less likely to acquire the linguistic competence and social mores needed to become members of a separate deaf-blind culture.

In some parts of the United States, communities of deaf-blind people are forming. Groups can be found in Seattle, Washington; Minneapolis, Minnesota; Columbus, Ohio; Baton Rouge, Louisiana; and Washington, D.C. More likely for the typical United Methodist Church and its respective localities, there will

<sup>5</sup> An estimated 3 to 6 percent of children born deaf, and the same percentage of children born hard of hearing, have Usher Syndrome. Type 1 defines those born deaf or with profound hearing loss; type 2 refers to those born hard of hearing; and type 3 describes those born with hearing or mild hearing loss that worsens progressively over a decade or more. In each case there is an accompanying and progressive loss of eyesight due to *retinitis pigmentosa*. Usher Syndrome will be discussed more fully on page 65.

<sup>6</sup> Information for this section was gleaned from correspondence with Dorothy Walt, Northwest Regional Representative of HKNC, and Michael Brennan, an affiliate of HKNC on the faculty of Alliant International University in San Diego, California.

be only small pockets of deaf-blind people. Regardless of the number, these people, as is the case with all human beings, are to be engaged in the church's life and work.

## **HOW DO DEAF-BLIND PEOPLE COMMUNICATE?**

How do deaf-blind people communicate with others? The short answer is "in many different ways, depending on each person's hearing and seeing circumstances." Following is a compilation of ways deaf-blind people may choose to "send and receive" messages.<sup>7</sup> The list is categorized according to whether the person communicating with the deaf-blind individual needs special knowledge and whether special equipment is required. Note that deaf-blind people who have some usable vision and/or hearing may use *American Sign Language* (if culturally deaf), *speechreading*, *cued speech*, and/or *assistive listening devices*.

### **No Special Knowledge or Equipment Needed to Communicate with Deaf-Blind Person**

#### ***Print-on-Palm***

This involves drawing block capital letters on the deaf-blind person's palm, one letter atop another.

#### ***Pad and Pen***

Some deaf-blind people can read text written with a thick dark pen.

#### ***Tadoma (Tactile Speechreading)***

Tadoma is named after the first two children to whom it was taught (Tad Chapman and Oma Simpson). The deaf-blind person places his or her thumb on the speaker's lips and his

or her fingers along the speaker's jaw, cheek, and throat to pick up lip movements and speech vibrations. This method is difficult for the deaf-blind person to master and is not very accurate.

### **Special Knowledge Needed**

#### ***Restricted Field Signing***

Also called Visual Frame Signing, this is used by Deaf people with "tunnel vision" (as in retinitis pigmentosa from Usher Syndrome); it is like standard signing except that the signer's hands are kept near the upper body and face so they do not move outside the range of the deaf-blind person's field of vision.

#### ***Tracking Signing***

Often used by people with "tunnel vision" due to Usher Syndrome; the deaf-blind person holds the signer's forearms in order to know where to look to see the signs.

#### ***Tactile Sign Language***

The deaf-blind person puts her hands on the hands of the person signing in order to feel their shape, position, and movement.

#### ***Tactile Fingerspelling***

Letters are fingerspelled into the palm of the deaf-blind person; culturally deaf people seldom use this method because it is based on the grammar of English (or another spoken language).

#### ***Finger Braille***

The deaf-blind person holds out six fingers like the keys on a braille, and the "sender" press-

<sup>7</sup> Much of this list is based on information from "The Deaf-Blind FAQ" ([http://www.eng.cse.dmu.ac.uk/~hgs/deafblind/deafblind\\_faq.html](http://www.eng.cse.dmu.ac.uk/~hgs/deafblind/deafblind_faq.html)) and "About Deaf-Blind" by Andrea Papillon ([http://www.drc-fredericksburg.org/progressctr/deaf\\_deafblind.html](http://www.drc-fredericksburg.org/progressctr/deaf_deafblind.html)).

es the fingers down as if embossing Braille; this method is not widely used in the U.S.

### **Special Equipment Needed**

#### ***Alphabet Glove***

This is a white glove with the alphabet written on it; the deaf-blind person learns the positions of the letters, and the person communicating presses the appropriate ones.

#### ***Alphabet Card***

This is an index card with raised letters of the alphabet; the deaf-blind person's index finger is placed on the desired letters.

#### ***The Brailletalk (Braille Alphabet Card)***

This is a plastic box about the size of a postcard that opens like a book to display letters above braille characters; the deaf-blind person's finger is placed on the braille character below the appropriate letter.

#### ***Braille***

This may be used for communication by deaf-blind people who learned braille before losing their hearing. One approach uses the Tellatouch, a device that displays one cell of braille at a time when keys on the typewriter keyboard are pressed. A faster (but more expensive) method uses the TeleBraille, a TTY typewriter keyboard with visual display connected to a braille keyboard with braille display. When letters are typed, they are displayed as braille characters on the braille display, and messages keyed in braille are displayed as letters on the typewriter's visual display.

## **MINISTRY WITH DEAF-BLIND PEOPLE**

Churches in large cities may discover a concentration of deaf-blind people living in their localities. If so, a church or several churches cooperatively can reach out to that deaf-blind populace. For most churches, there may be only a small number of deaf-blind people—if any—living in their communities.

Perhaps to a local church's surprise, the deaf-blind condition may arise in one or more of its members. Given the longer life expectancy in the U.S., there is an increased likelihood that members will become hard of hearing or deafened and partly or fully blind. If that happens, the pastoral staff and laity will want to guard against letting such people isolate themselves from the church. Steps must be taken to make church involvement fully accessible to these new deaf-blind folk. For the church to dismiss them as "homebound" is a shameful disregard of God's call to ministry with these differently hearing and seeing members.

To prevent abandonment of deaf-blind people, the local church needs to examine its attitude toward all people living with various kinds of physical and emotional challenges, including those who—at any age—are losing their sight and hearing. The local church must remove physical and attitudinal barriers that deny full participation in the church's life and work.

Not only should the church heed God's call to serve the needs of deaf-blind people; it is also crucial that the local church understand it is the poorer if its ministry is not extended to all people, including those who are deaf-blind. All of its members are diversely "gifted" by the Holy Spirit for ministry, and to deny itself the full presence and participation of these gifted members is to demean both God and itself.

Many who live with deafness and blind-

ness can develop unique insights and skills that serve the body of Christ. Deprived of full visual and auditory senses, such people may find themselves relying more and more on the power of introspection as they grasp and manage life. Such practice can enhance insight and understanding in distinctive and helpful ways. Antoine de Saint-Exupéry in *The Little Prince* said: "It is with the heart that one sees rightly; what is essential is invisible to the eye." The church should welcome the privilege of ministering to and receiving ministry from all people.

The following is an excerpt from a letter by Dr. Peggy Johnson:

...deaf-blind people, as with all people, are uniquely gifted for ministry and mission. They are not here just to be the poor, pitiful recipients of our charity and acts of access. When empowered they have much to offer the church in terms of their insights on spiritual issues, and a variety of other gifts, some because of their deaf-blindness and [some for other reasons]. But, it is a challenge to the church always to see [deaf-blind people] as the gift, not the mission project. As we turn the tables around and allow them to be our teachers, we are getting close to Christ's beatitude craziness in Matthew 5:1-11.<sup>8</sup>

### "An Ordained Minister's Story"<sup>9</sup>

From my earliest cognitive moment I knew I was hard of hearing; I did not then know I was also partly blind. My hearing loss, I thought, was because of mastoiditis (infection of the mastoid bone resulting from a spreading middle ear infection) at the age of two, resulting in a double mastoidectomy (removal of the mastoid air cells). Such surgery wasn't uncommon, performed as the best-known way to cure chronic ear infections.

My brother, older by two years, was also hard of hearing. The culprit in his case was thought to be whooping cough at a tender age. It wasn't until each of us was a young adult that we learned more about the cause of our deafness.

Meanwhile, hearing loss was a dominant reality in our childhood and youth. I was deemed to have had the greater loss, and when I was about 10 years old an eye, ear, nose, and throat doctor used experimental surgery and other treatments in a vain effort to restore my hearing. Surrendering to the invincibility of my hearing loss, the doctor prescribed a hearing aid, which I first wore at the age of 11. Since then I have moved within the hearing world assisted by progressively improved electronic aids. My brother, thought to have heard better than I, wasn't fitted with a hearing aid until late in his high school years. He also relied on these instruments until his death in 1985.

We were never sent to the state school for deaf children but were "mainstreamed" in public schools, long before that term was popularly applied to children with "special needs." Our passage through those years wasn't easy, frequently accompanied by misunderstanding and being mistaken as "slow" due to our poor hearing and speech skills. Nonetheless, we each went on to college. My brother became a pharmacist, while I attended seminary and earned a Doctor of Ministry degree several years later at a second seminary. Increasingly powerful hearing aids and three separate programs of speech therapy accompanied me in my educational and professional journeys.

As children and teenagers, my brother and I did not realize we were also coping with limited vision. Looking back, I now understand why I was a frequent dud in hide-and-seek games played after dusk, or why I could discern stars but seldom the intricate constellations visible to

<sup>8</sup> From a letter dated November 30, 2000, to the author.

<sup>9</sup> The account is by the Rev. Dr. Robert Walker, author of this Part.

others. My brother was my twin, as it were, in not seeing well when evening came.

During our college years, we each learned from ophthalmologists that we had retinitis pigmentosa (RP). Little was known about it, and no doctor linked the disease to our loss of hearing. Its effect, however, proved increasingly limiting. RP causes "tunnel vision." Lacking peripheral scope to our field of vision, we missed details in objects or scenes outside the edges of sight. Certain games and skills evaded our eyes' reach.

It wasn't until the late 1960s that we learned that our loss of hearing and disappearing eyesight were linked. The paired symptoms suggested Usher Syndrome. In the late 1990s, researchers analyzing my DNA verified the diagnosis and placed me in Type 2. Today, I'm a member of a rare group of 12,000 people in the U.S. coping with Usher Syndrome.

Named for the scientist who identified the cause of this congenital disease, Usher Syndrome is caused by a gene that has "deleted" a specific protein necessary for healthy development of both the *cochlea* (the inner ear) and the *retina* (the membrane at the back of the eye that transmits light signals to the brain). The retinal condition, retinitis pigmentosa, moves gradually from the periphery to the center, causing "tunnel vision."

The syndrome is caused by a recessive gene, meaning that both parents must be carriers of that faulty gene. Children of a parent who has Usher Syndrome are inevitably carriers, but will not themselves have the syndrome unless the other parent is also a carrier or living with the syndrome. Fortunately, none of my brother's descendants or mine has the syndrome.

It was a relief for my brother and me to name the problem; it was unsettling to be told there was no cure for either of our progressive sensory losses. Our only recourse was to live with the

syndrome, imperfectly helped by amplification and magnification devices, all designed to bring sound and light into what can be a progressively silent and darkened world.

There was another, intangible source of help for my brother and me. The church, distributor of the good news of God's undeterred hospitality toward all people irrespective of their circumstances or society's assessment of them, remained hospitable to us. From the time of our baptism as infants on into adulthood, we had a home within the church. As a layperson and worshiper, my brother provided hours of service in various capacities, until he was stopped by amyotrophic lateral sclerosis (Gehrig's disease), which caused his death.

It was my privilege to serve as a pastor for 42 years, retiring a year and a half early due to increasing blindness. Now and then there was a bishop or two and some superintendents who were uncertain about appointing a pastor who could not see or hear well to a local church. Not surprisingly, a few parishioners here and there were also suspicious of a "handicapped pastor." However, the majority in those churches overcame whatever qualms they might have had, allowing pastor and congregation to forge a collegial ministry in the church and its community.

That spirit of collegiality proved essential in the late 1970s as RP took its inexorable toll on my eyes. Until then, I had continued to drive an automobile, but only in daylight. One day that which I dreaded happened: out on some pastoral business in my car, I struck a woman on a crosswalk. I never saw her until it was too late. Her leg was severely broken, requiring her to spend a few days in the hospital. On a regular visit to hospital patients later that week, I went to see the woman. Her fiancé was there as well. I expressed my sorrow for the accident, and our brief visit was pleasant.

Some weeks later, the woman telephoned

me from her home, saying that she and her fiancé were planning their wedding. I was, she said, the only minister she knew. Would I please perform the ceremony? Of course I did. A month or so after that, the couple who served as their best man and maid of honor asked me to conduct their wedding service. I must say, causing an accident is hardly a preferred means of creating an opportunity for pastoral care! The incident, however, remains a model of reconciliation among disparate folk, willed by God in Christ.

From that time on, I ceased driving automobiles. To get about in the community for pastoral responsibilities and community service, I relied not only on my wife but also on a cadre of retired church members who were uniformly pleased to serve as my chauffeurs. Whether due to physical challenges or not, such pooling of gifts between the ordained and lay servants of God exemplifies the model of collegial ministry created by Jesus and his disciples.

Clearly, all who accept Christ's call to be his ongoing earthly body in God's cherished world have gifts to share, and none should be barred by being labeled "disabled." It remains the passionate premise of *Signs of Solidarity* that deaf-blind people—along with those who are Deaf, late-deafened, or hard of hearing—shall not be denied the serving of their needs or the exercising of their gifts as the body of Christ.

## **ACTS OF HOSPITALITY TOWARD DEAF-BLIND PEOPLE**

Prominently displayed throughout the Hebrew Bible and the Christian gospels and epistles is the theme of hospitality. Etymologically, the word refers to a welcoming place of rest for renewal of strength, and a place for all people. The spirit of hospitality invites all to

"come in and be at home" in our lives and in the church.

Alluding to Lot's interrupted effort to show hospitality to strangers (Genesis 19), the book of Hebrews sees the Christian style as always being hospitable to strangers. "Do not neglect to show hospitality to strangers, for thereby some have entertained angels unawares" (Hebrews 13:2). Let "stranger" serve as a metaphor for all people judged to be different from the "norm." The church that follows the way of Christ will be hospitable to all, whether or not they are seeking spiritual nourishment and strength. Without exception or restriction, the church shall invite "strangers"—including deaf-blind people—to "enter and be at home."

Following are a few suggestions for the church that seeks to welcome people who are deaf-blind. Also, the Accessibility Audit for Ministry on page 93 guides the church in making its facilities and programs "hearing-accessible."

1. *Learn the story, needs, and gifts of the deaf-blind people in your church and community.* Each person living with deaf-blindness is different. Volunteers may be recruited to work with the pastoral staff in discerning the deaf-blind person's life journey, needs, and gifts. Specifics gleaned from the interview will guide the church in tailoring its response appropriately. It is crucial for the church to learn what helps and what hinders the deaf-blind person's engagement in worship, education, tasks, and fellowship within the church.

2. *Supply needed audio and/or visual aids.* The hospitable church will learn from its deaf-blind sisters and brothers in Christ what specific aids are needed. Some will require tactile interpretation. Unlike sighted deaf people, each deaf-blind person requires her own interpreter, who

may be a volunteer or a paid professional. To be an effective interpreter for deaf-blind people, the tactile signer must be well trained in the art of signing and understand the church's liturgical and theological language. Deaf people fluent in sign language make good tactile interpreters; they receive the message from an interpreter and relay it to the deaf-blind parishioner. Other deaf-blind people may have sufficient residual hearing and visual acuity to benefit from assistive listening devices, large-print materials, and the like. Those who have some hearing but see very poorly or not at all are not helped by printed or projected materials, drama without dialogue or narration, or other visual effects. Instead, they require aids such as assistive listening devices and *secondary audio programming* (SAP) description of unspoken activity. Those who can see after a fashion but hear little or nothing require similar support through visual aids. Audiovisual aids must be available in the sanctuary, fellowship hall, meeting rooms, and classrooms. These aids should be routinely brought to the deaf-blind person, who should not have to go in search of the specific tool(s).<sup>10</sup>

3. *Provide volunteer guide service.* A deaf-blind person may be accompanied by a spouse, other family member, or close friend to gatherings outside the home. Such a companion provides volunteer guide service as needed in public facilities like the church. Other deaf-blind folk may be alone and need trained volunteer guides. The guide should not take a blind person's arm and push him or her ahead; rather, the guide should offer an arm which the blind person grasps near the elbow to be led to a pew, chair, meeting room, rest room, etc. The guide steers the blind person around hazards and warns of steps. If the blind person arrives

at church on a bus or other public transportation, the guide meets him or her at curbside and is an escort until that service is no longer needed. Here, as in all other cases with deaf-blind people, effective communication determines the extent of assistance needed from the volunteer guide. The sensitive guide will avoid providing too little or too much help.

4. *Educate the church members on manners that help the deaf-blind person feel the church's hospitality.* Brief announcements, newsletter articles, and the Sunday bulletin can be used to encourage appropriate actions. One deaf-blind person expressed her frustration over the many people in church who greet her by saying "Hi!" but fail to identify themselves or even indicate that they are speaking to her. Deaf-blind people cannot be expected to approach people to make conversation; they should be approached by the seeing church members, telling the deaf-blind person either directly or through an interpreter who they are. When the seeing person leaves, that should be told to the deaf-blind person, who otherwise is left in the embarrassing position of talking to a person no longer present. Touch helps; a hand placed on the arm or hand of the deaf-blind person makes it clear that he or she is being greeted; for departing, another touch is helpful. And, it is always appropriate for anyone visiting with a deaf-blind person to ask whether the individual needs personal assistance.

5. *Recruit deaf-blind people for leadership roles.* Deaf-blind folk can provide gifts of leadership by serving as preachers, teachers, committee and board chairpersons members, and more. These positions can be in the local church, district, and conference and within the general boards and agencies of the church. Some deaf-

<sup>10</sup> Parishioners and church leaders have been known to object to the use and positioning of interpreters and visual aids as being detrimental to the aesthetics of the sanctuary or meeting room. What finally is more important, a room's appearance or a parishioner's ability to participate in worship and other acts of the church's life and work?

blind people, of course, may not wish to take a specific assignment; however, let the deaf-blind person, not the nominating committee, make that decision.

6. *Be observant of unmet needs.* Careful observation by the church staff, officers, and members of the deaf-blind person's specific limitations, plus common sense and caring, can direct the church in specific acts to enable the deaf-blind person's involvement in the church's life and work. As is the case with nearly everyone, deaf-blind people may be hesitant to ask for help and may not divulge every need. At times, they need others to speak up for them, but they can also use encouragement to be more assertive about their needs and about stating what helps them. On page 74, a section on Resources is provided. Additional information and helpful advice may be acquired from the organizations listed there.

## **THE "GREAT COMMISSION" APPLIED**

Matthew's story of Jesus—that remarkable seer and hearer of God's will for a humane humanity—concludes with what the church calls the "Great Commission." The risen Christ tells his new earthly body, the church: "Go therefore and make disciples of all nations, baptizing them in the name of the Father and the Son and the Holy Spirit, and teaching them to observe everything that I have commanded you" (Matthew 28:19-20a).

Might not "nations" be understood as more than political or geographical entities but also metaphorically as richly diverse groups of race, ethnicity, gender, age, economic circumstances, and physical and mental challenges? If so, then let the Deaf, late-deafened, hard of hearing, and deaf-blind populations each be considered a "nation." The church is therefore to make disciples of each, including those who are deaf-blind.

When the church can hear and see that wisdom, then is the blessing fulfilled of which Jesus spoke: "And remember, I am with you always, to the end of the age" (Matthew 28:20b).



# Ephphatha! Be Opened!

*For just as the body is one and has many members, and all the members of the body, though many, are one body, so it is with Christ....*

*Now you are the body of Christ, and individually members of it.*

1 Corinthians 12:12, 27  
(NRSV)

Paul exhorts us to inclusion in these verses. Jesus' teachings show us the better way, a way to rise up from separation, from sin, to wholeness and unity. His is a most inclusive message.

What does inclusivity mean when a different culture, such as Deaf culture, is involved? What does it mean when a person simply cannot hear well or is late-deafened (deaf but grew up hearing), or is hard of hearing and blind? Are they not also the children of God? In my father's house there are many rooms (John 14:2 NIV).

Accepting our differences, growing and learning from one another, opening to different ways of communication—and to different ways of living—have benefits of their own. As Rev. Dr. Thomas Hudspeth writes in his doctoral thesis "ASL as a Means of Grace," congregation members often find the sermon enhanced when interpreted or signed in American Sign Language. The following excerpt from his thesis expands on the benefits inclusion of Deaf people can bring:

As a prudential means of grace,<sup>1</sup> American Sign Language became a gift for First United Methodist Church, Marshall, Texas. This visual and kinesthetic gift gave a new means of spiritual, self-expression to God as well as introducing the congregation to a

community for which God has great concern and love: the Deaf neighbor. Through American Sign Language, First United Methodist, Marshall experienced John Wesley's emphasis on uniting love of the Divine Other with love for others. In this sense, ASL can lead one to a saving relationship with God in Christ.

Two testimonies at a workshop, which I led at the Methodist Mission Home in San Antonio, illustrate the saving grace of American Sign Language. I was with eighteen other people, all Deaf, hard of hearing, or hearing, who had gathered for the biennial meeting of the South Central Jurisdiction of the United Methodist Congress of the Deaf.

I asked the group to break up into smaller groups to share their experiences with ASL. To those who were hearing, I asked, "Why do you use ASL? How did you feel when you first saw ASL?" To those who were Deaf, I asked, "How did you feel when you saw a hearing person use ASL?"

One Deaf woman signed: "I thought I was the only person in town who was Deaf. But one day, I was at the driver's license office, waiting in line, signing to my mother. Suddenly, another woman came up to me and signed, "Are you Deaf?" I was shocked! I signed back to her, "Where did you learn ASL?" This young Deaf woman went on to share how this hearing woman had signed to her about learning ASL at First United Methodist Church, Marshall. About six months later, this Deaf woman joined First United Methodist, Marshall, and had her infant son baptized on Easter Sunday.

<sup>1</sup> Prudential means of grace are those actions that are not commanded by Scripture but are helpful to one's relationship in Christ. This term was coined by John Wesley to distinguish these means of grace from those instituted by Christ, i.e. prayer, Scripture reading, fasting, the Lord's Supper, and Christian conferencing.

I then asked the group to share "How has ASL increased your love for God and for others?" Immediately one of our interpreters, a young woman, blurted excitedly, "That's my story!"

Though her father was Lutheran and her mother Catholic, she did not grow up going to church. When she went to a college in Arizona, she learned several different languages, but then she saw ASL and fell in love with the beauty of the language. During this time, she was seeking a deeper spiritual relationship apart from the Christian faith. She experimented with Buddhism and the Wiccan religion. (At some point she also married. A friend of her husband asked him if she would be willing to interpret at his church. She accepted this indirect appeal.)

When she came during her first year to the worship service, she came strictly to interpret the service and to earn some money. Not having a relationship with Christ, she felt somewhat awkward at Christian gatherings. Then about two months before coming to the workshop at San Antonio, she received her conversion. Smiling, she said, "My life has taken a dramatic change—I see everything so differently." Signing through the air with vigor, she added, "Now when I sign 'hallelujah,' I know how to REALLY sign HALLELUJAH!" Reflecting upon her life, this interpreter saw how through ASL, God had reached her. If not for ASL, she would have never stepped into a church, nor would she have experienced the tremendous joy for her newfound faith.

When we consider that the Christian faith is incarnational, as declared in the Gospel of John: "The Word became flesh and made his dwelling among us" (1:14, New International Version), we can appre-

ciate the affinity of ASL as a "language of the flesh" to complement and express Christian spirituality. As people, especially hearing people, are exposed to ASL in worship, it is not surprising that God's grace has "tapped them on the shoulder."

In a similar vein, graphic notetaking assists everyone in the meeting to understand what is being accomplished. Placing the text of sermons on a screen for all to see aids the congregation in better absorbing the intended message. When the congregation begins to understand that changes necessary to make worship services accessible to Deaf, late-deafened, hard of hearing, and deaf-blind people are enhancing the services for all people, a major step towards inclusion will have been taken.

But more is needed for full inclusion to occur. Full inclusion means being open to a person who is different, open to that person as a person of worth—an individual with his or her own gifts and needs. It means facilitating full integration of a late-deafened individual into the church. It means encouraging and supporting a separate Deaf church. It means seeing communication as a responsibility of all parties involved in the conversation. Rev. Dr. Robert Walker refers to the lack of full inclusion of Deaf, late-deafened, hard of hearing, and deaf-blind people in the United Methodist Church as its attitudinal deafness.

Attitudinal deafness is what Holly Elliott spoke about in paraphrasing Matthew 25:31-46 at the United Methodist General Conference of 1992 (see excerpts below) when she asked for legislation to form a committee to survey deaf ministries (this became the National Committee on Ministries with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People):

Then the Holy One shall say to the people on the right:

"You who are blessed by my Maker come and receive the birthright that has been prepared for you ever since the creation of the world:

I was deaf and you provided sign language interpreters.

I was hard of hearing and you gave me assistive listening devices...

I was vision-impaired and you bought an enlarging copier machine...

I had no voice and you gave me a funded conference task force."

And the righteous will then respond:

"Friend, when did we ever greet you in the sign language of the deaf? Or provide you with FM or infrared transmitters?...

"Yes, and when did we share the burden of your diminished eyesight...? And when did we support your advocacy with a task force?"

The Holy One will answer them:

"I tell you, indeed, whenever you did this for any of these my brothers and sisters, you did it for me."

Rev. Dr. Walker spoke of the church's ears becoming opened when its attitudinal deafness is healed:<sup>2</sup>

In Mark's story,<sup>3</sup> Jesus exclaimed "Ephphatha!"—Aramaic for "be opened!"—to the man who could not hear well. Let Jesus' command be exclaimed now to those who are spiritually deaf to God's love that makes them whole, despite their physical

hearing loss. And let "Ephphatha!" be exclaimed to the church that has not heard the way Deaf, late-deafened, hard of hearing, and deaf-blind people hear. Those who are culturally Deaf hear, with eyes and hands, their own unique American Sign Language (ASL). Deaf-blind people may hear with a tactile version of sign language or finger-spelling (signed into the palms of their hands). Oral deaf persons hear through speechreading and visual aids. Late-deafened people hear with visual aids such as captioning, and hard of hearing people hear with hearing aids, assistive listening devices, and visual aids.

The community around the deaf man in Mark's story was itself deaf until it heard, and helped the Deaf man hear, the Good News of God's all-inclusive love. Any church today is remiss in doing the "works of God" when it turns a deaf ear on Deaf, late-deafened, hard of hearing, or deaf-blind people.

Let it also be said that every church is "hearing" when it welcomes the healing of its own attitudinal deafness. With its ears now open, as the Deaf man's ears were opened, that church will hear its own ministry and mission with person who live, worship, and serve—despite their hearing loss—as gifted members of Christ's ever-new earthly body (1 Corinthians 12:27).

The "opening" of the church's ears depends on the full inclusion of Deaf, late-deafened, hard of hearing, and deaf-blind people as children of God. *For in the one Spirit we were all baptized into one body – Jews or Greeks, slaves or free – and we were all made to drink of one Spirit.*

(1 Corinthians 12:13 [NRSV])

<sup>2</sup> From Walker, Robert, "Let All Who Will, Hear" in *Breaking the Sound Barrier in Your Church: Ministry and Mission with People Who Are Hard of Hearing and Late-Deafened*, distributed by the Health and Welfare Ministries Unit, General Board of Global Ministries, The United Methodist Church.

<sup>3</sup> Mark 7:34.

# Conclusion

This resource has discussed a wide range of ministries that are possible for local churches, districts, and annual conferences. As you further your journey in ministry with people who are Deaf, late-deafened, hard of hearing, or deaf-blind, you will want to move slowly but intentionally. It is difficult to say exactly where to begin. Some start with the immediate needs of their local church. Others want to focus on an outreach ministry to the community.

At some point along the way, you will need to decide what particular focus your ministry will have: the long-term goal of establishing a Deaf church or an attempt to target the needs of a special constituency, such as Deaf youth, Deaf children in residential schools, hard of hearing older adults, deaf-blind individuals, or those who have become late-deafened.

Below you will find a list of steps you can take once you have determined your focus. The list is not in any special order. Of necessity, several stages in the process will happen simultaneously. Neither is the list exhaustive. You may have ideas you would like to add to it. Here are the ways you can get started.

## Learn

- Read as much as you can about the issues.
- Send for information from the various organizations listed.
- Borrow videos from lending libraries.
- Contact churches with a similar focus to get more specific guidance.
- Sponsor workshops and invite outside speakers so that you will have the best foundation possible for your ministry.

## Survey

- Study the needs of the Deaf, late-deafened, hard of hearing, and deaf-blind members of your community.
- Survey the human resources you have that will enable this new ministry to run smoothly.
- Determine the available financial resources with which you can underwrite your program.
- Seek out Deaf, late-deafened, hard of hearing, and deaf-blind people who can provide leadership and guidance for your congregation as you make important decisions. Choosing leaders from the community to be served will ensure that whatever ministry you establish will be appropriate to the desires of the particular community.
- Find hearing people who have skills in sign language, the ability to work with people, or experience with family members who have some degree of hearing loss.
- Once the focus has been determined, recruit hearing people who would like to play a service role.

## Recruit

- Caretakers for the assistive listening system to make sure that it is in proper working order and that receiver batteries are charged.
- Good typists to be computer-assisted notetakers.
- Good storytellers for Sunday school classrooms.
- People willing to be trained as oral interpreters.

- Tactile interpreters if needed for deaf-blind churchgoers.
- Artistic notetakers for graphic notetaking.

### **Pray**

- Spend time in prayer about your reasons and motivations for establishing this ministry.
- Ask God for strength, wisdom, and humility as you establish a ministry that is based

on solidarity and equal partnership with your constituents.

- Pray for the wisdom to welcome and honor the various gifts that people will bring to this new ministry.

Above all, be creative! Experiment with new models that will benefit your particular situation, and celebrate the new community that will emerge.

# Resources

(Note: Out-of-print titles may be available from libraries or other sources.)

## THEOLOGY OF DISABILITY

Eiesland, Nancy. *The Disabled God: Toward a Liberatory Theory of Disability*. Nashville: Abingdon Press, 1994.

## CULTURALLY DEAF RESOURCES

### Books

Benderly, Beryl Lieff. *Dancing without Music: Deafness in America*. Garden City, NY: Anchor Press/Doubleday, 1980 (republished by Gallaudet University Press, 1990).

Chambers, Diane P. *Communicating in Sign: Creative Ways to Learn American Sign Language*. New York: Simon and Schuster, 1998.

Christenson, Katheen M. and Delgado, Gilbert L. *Multicultural Issues in Deafness*. White Plains, NY: Longman, 1993.

Costello, Elaine. *Signing*. New York: Bantam Books, 1983.

Costello, Elaine. *Religious Signing*. New York: Bantam Books, 1986.

Fant, Lou. *The American Sign Language Phrase Book*, rev. ed. Chicago: Contemporary Books, 1994.

Gannon, Jack R. *Deaf Heritage: A Narrative History of Deaf America*. Silver Springs, MD: National Association of the Deaf, 1981.

Gannon, Jack R. *The Week the World Heard Gallaudet*. Washington, DC: Gallaudet University Press, 1989. (Recounts the 1988 student protest demanding the appointment of a Deaf president for the university.)

Glickman, Neil S. and Harvey, Michael A. *Culturally Affirmative Psychotherapy with Deaf Persons*. Mahwah, NJ: Lawrence Erlbaum Associates, 1996.

Lane, Harlan, Hoffmeister, Robert, and Bahan, Ben. *A Journey Into the Deaf-World*. San Diego, CA: DawnSignPress, 1996.

Lane, Harlan. *The Mask of Benevolence*. New York: Alfred A. Knopf, 1992 (republished by DawnSignPress, 1999).

Lane, Harlan. *When the Mind Hears: A History of the Deaf*. New York: Random House, 1984.

National Association of the Deaf. *Legal Rights: The Guide for Deaf and Hard of Hearing People*, 5th ed. Washington, DC: Gallaudet University Press, 2000.

Neisser, Arden. *The Other Side of Silence: Sign Language and the Deaf Community in America*. New York: Alfred A. Knopf, 1981 (republished by Gallaudet University Press, 1990).

Padden, Carol, and Humphries, Tom. *Deaf in America: Voices from a Culture*. Cambridge, MA: Harvard University Press, 1988.

Sacks, Oliver. *Seeing Voices: A Journey Into the World of the Deaf*. Berkeley, CA: University of California Press, 1989 (republished by Vintage Books, 2000).

Schein, Jerome. *At Home among Strangers: Exploring the Deaf Community in the United States*. Washington, D.C.: Gallaudet University Press, 1989.

Schwartz, Sue, ed. *Choices in Deafness*, 2nd ed. Bethesda, MD: Woodbine House, 1996. (Discusses options for parents.)

Van Cleve, John Vickrey, and Crouch, Barry A. *A Place of Their Own: Creating the Deaf Community in America*. Washington, DC: Gallaudet University Press, 1989.

## **Videotapes for Purchase**

### Sign Language and Deaf Culture Videotapes

*American Sign Language Basics for Hearing Parents of Deaf Children* by Jan Kelly-King and Jessey Freeman King (two videotapes, 128 minutes; plus a study guide). Available from: Butte Publications, Inc.

P.O. Box 1328

Hillsboro, OR 97123

503-693-9526 (Fax)

service@buttepublications.com

www.buttepublications.com.

Sign Media

4020 Blackburn Lane

Burtonsville, MD 20866

800-475-4756 301-421-0268

www.signmedia.com

Sign Media produces a variety of videotapes on American Sign Language, interpreting, and Deaf culture, including:

*An Introduction to American Deaf Culture* (five videotapes and workbooks by M. J. Bienvenu and Betty Colonomos).

*Deaf Awareness Orientation Package* (three open-captioned videos, which can also be purchased separately):

*An Introduction to the Deaf Community*  
by Patrick Graybill and Dennis Cokely  
*Using Your TTY*

*Working with a Sign Language Interpreter*

*Interpreters on Interpreting* (six videotapes and transcripts by Sharon Neumann Solow and Lou Fant).

*Parent Sign Series* (videotapes with language and activities for hearing families with a Deaf child).

*Signing Naturally* (teacher's curriculum guidebook and videotape for levels 1, 2, and 3) by Cheri Smith, Ella Mae Lentz, and Ken Mikos can be purchased from:

DawnSign Press

6130 Nancy Ridge Drive

San Diego, CA 92121

858-625-0600 Voice/TTY

www.dawnsignpress.com.

### Religious Videotapes and Other Religious Resources

*The Gospel of Luke: An ASL Translation* (five 90-minute videotapes). Available from Sign Media, Inc. (Contact information given under Sign Language and Deaf Culture Videotapes).

*Mark: A Study of the Gospel of Mark in American Sign Language* by Rev. Val Dively. Available from:

Cokesbury

PO Box 801

Nashville, TN 37202

800-672-1789 Voice

800-227-3091 TTY

[www.cokesbury.com](http://www.cokesbury.com).

For more information, call Curric-U-Phone, 800-251-8591 Voice.

Videos by Deaf Christian concert artist Mark Mitchum, featuring songs (signed in ASL with voice-over and music; transcripts available), instructions for church interpreting, and ASL sermons, available from:

Heartland Ministries, Inc.

P.O. Box 14196

Arlington, TX 76094

817-465-5405

817-557-0578 Fax

<http://home.att.net/~MarkMitchum/catalog.htm>

Videos (and other resources) on religious topics can also be purchased from:

Deaf Missions

2119 Greenvview Road

Council Bluffs, IA 51503

712-322-5493 Voice/TTY

[www.deafmissions.com](http://www.deafmissions.com)

Deaf Video Communications

25W560 Geneva Road, Suite 10

Carol Stream, IL 60188-2231

630-221-0909 Voice

630-221-9093 TTY/Fax

[www.deafvideo.com](http://www.deafvideo.com)

The Mill Neck Foundation for Deaf Ministry

Frost Mill Road

P.O. Box 100

Mill Neck, NY 11765

800-264-0662 Voice/TTY

[www.millneck.org/frmwelc1.htm](http://www.millneck.org/frmwelc1.htm)

National Catholic Office of the Deaf

7202 Buchanan St.

Landover Hills, MD 20784

301-577-1684 Voice

301-577-4184 TTY

[www.ncod.org](http://www.ncod.org)

National Council of Churches of Christ

Deaf Ministry Committee

c/o Beth Lockard

Christ the King Lutheran Church

730 S. New Street

West Chester, PA 19382

### **Videotapes Available as Rentals**

The following audiovisuals dealing with family issues are obtainable through video stores:

*And Your Name Is Jonah.* Hearing parents teach their Deaf child to sign.

*Beyond Silence.* A German girl with Deaf parents develops her musical talents.

*Bridge to Silence.* After her husband is killed in an accident, a Deaf woman is involved in a child custody fight with her hearing parents.

*Children of a Lesser God.* Hearing teacher at school for the Deaf falls in love with a young Deaf woman who works there as a janitor.

*In the Land of the Deaf* (French with English subtitles). Documentary shows life experiences of Deaf people of all ages.



*Love is Never Silent* (TV movie). A hearing child grows up with Deaf parents.

*Mr. Holland's Opus*. A high school music teacher's relationship with his Deaf son is one element in the plot.

*Sound and Fury*. Documentary portrays a hearing family's struggle to convince Deaf parents to allow their six-year-old Deaf daughter to receive a cochlear implant.

### **Secular Organizations That Offer Resources**

Canadian Association of the Deaf  
2435 Holly Lane, Suite 205  
Ottawa, ON K1V 7P2  
613-526-4785  
613-526-4718

Gallaudet University  
Office of Public Relations  
800 Florida Ave., NE  
Washington, DC 20002  
[www.gallaudet.edu](http://www.gallaudet.edu)

Info to Go  
Laurent Clerc National Deaf Education Center  
Gallaudet University  
800 Florida Avenue NE  
Washington, DC 20002  
202-651-5051 Voice  
202-651-5052 TTY  
<http://clerccenter.gallaudet.edu/InfoToGo>

National Association of the Deaf  
814 Thayer Avenue  
Silver Spring, MD 20910  
301-587-1788 Voice  
301-587-1789 TTY  
[www.nad.org](http://www.nad.org)

Registry of Interpreters for the Deaf  
(information on locating certified interpreters)  
8630 Fenton Street, Suite 324  
Silver Spring, MD 20910  
301-608-0050 Voice/TTY  
[www.rid.org](http://www.rid.org)

Telecommunications for the Deaf, Inc. (TTY and relay information)  
8630 Fenton Street, Suite 604  
Silver Spring, MD 20910  
301-589-3786 Voice  
301-589-3006 TTY

For information about using TTYs, see *Using Your TTY* under **Videotapes for Sale** in this section. For sources that sell TTYs, check the distributors listed under **Assistive Listening Devices or Systems** under **Hard of Hearing and Late-Deafened Resources** in this section.

### **United Methodist Deaf Ministry**

Johnson, Peggy, *The History of Christ United Methodist Church of the Deaf*, 1995. Includes information about the ministry of Rev. Daniel Moylan. For purchase information, contact: Christ United Methodist Church of the Deaf  
1040 S. Beechfield Avenue  
Baltimore, MD 21229.

Krafft, Beatrice Elliott Hasenstab, *A Goodly Heritage*. Columbus, Georgia: Brentwood Christian Press, 1989. Written by the daughter of Rev. Philip Hasenstab, it tells about her life growing up with her Deaf parents. Out of print.

VanGilder, Kirk, *The History of the United Methodist Congress of the Deaf*. Unpublished paper, 1999.

Current information on United Methodist Congress of the Deaf meetings, activities, and available resources may be obtained from:

National Committee on Ministries with Deaf,  
Late-Deafened, Hard of Hearing, and Deaf-  
Blind People  
Health and Welfare Ministries Unit  
General Board of Global Ministries  
The United Methodist Church  
475 Riverside Drive, Room 330  
New York, NY 10115  
212-870-3870

## **HARD OF HEARING AND LATE-DEAFENED RESOURCES**

### **Articles and Pamphlets**

Self Help for Hard of Hearing People (SHHH) list currently available articles and reports in its publications catalog (see **Organizations That Offer Resources** in this section for contact information).

The League for the Hard of Hearing has a list of pamphlets in its publications catalog (see **Organizations That Offer Resources** in this section for contact information).

### **Books**

Candlish, Patricia Ann Morgan. *Not Deaf Enough: Raising a Child Who Is Hard of Hearing with Hugs, Humor, and Imagination*. Washington, DC: Alexander Graham Bell Association, 1996.

Himber, Charlotte. *How to Survive Hearing Loss*. Washington, DC: Gallaudet University Press, 1989.

Harvey, Michael. *Listen with the Heart: Relationships and Hearing Loss*. San Diego, California: DawnSignPress, 2001. (Accounts by

a psychologist.)

Hogan, Anthony. *Hearing Rehabilitation for Deafened Adults: A Psychosocial Approach*. London: Whurr Publishers, Ltd., 2001.

Orlans, Harold, Ed. *Adjustment to Adult Hearing Loss*. San Diego, California: College-Hill Press, 1985.

Woodcock, Kathryn and Aguayo, Miguel. *Deafened People: Adjustment and Support*. Toronto: University of Toronto Press, 2000.

The following books can be purchased from the League for the Hard of Hearing (see **Organizations That Offer Resources** in this section for contact information):

Romoff, Arlene. *Hear Again: Back to Life with a Cochlear Implant*. New York: League for the Hard of Hearing, 2000. (Also available from SHHH.)

Ross, Mark, ed. *Communication Access for Persons with Hearing Loss: Compliance with the ADA*. York Press, Inc., 1994. (Also available from SHHH.)

Shuster, Bena. *Life After Deafness: A Resource Book for Late-Deafened Adults*. Ontario, Canada: Canadian Hard of Hearing Association (CHHA), 1995.

Suss, Elaine. *When the Hearing Gets Hard*. Insight Books, 1993.

The books listed below are available from SHHH (address under **Organizations That Offer Resources**):

Biderman, Beverly. *Wired for Sound: A Journey*

*Into Hearing*. Toronto: Trifolium Books, 1998. (Cochlear implants).

Carmen, Richard, ed. *The Consumer Handbook on Hearing Loss and Hearing Aids: A Bridge to Healing*. Sedona, AZ: Auricle Ink Publishers, 1998.

Dugan, Marcia B., *Keys to Living with Hearing Loss*. Barron's Educational Series, Inc., in collaboration with SHHH, 1997.

Harvey, Michael. *Odyssey of Hearing Loss: Tales of Triumph*. San Diego: DawnSign Press, 1999. (Accounts by a psychologist).

Myers, David G. *A Quiet World: Living With Hearing Loss*. Yale University Press, 2000.

Pope, Anne. *Hear: Solutions, Skills, and Sources for Hard of Hearing People*. Dorling Kindersley in collaboration with SHHH, 1997.

Rezen, Susan and Hausman, Carl. *Coping With Hearing Loss*. Rev. Ed. Barricade Books, 1993.

Thomsett, Kay and Nickerson, Eve. *Missing Words: The Family Handbook on Adult Hearing Loss*. Gallaudet University Press, 1993.

Wayner, Donna S. *Hear What You've Been Missing: How to Cope With Hearing Loss*. John Wiley Publishing, 1998.

### Audiotape

*The Unfair Hearing Test* demonstrates what it sounds like to have a hearing loss. Available from the League for the Hard of Hearing (see **Organizations That Offer Resources** in this section for contact information).

### Videotapes

The following videotapes are available from Self Help for Hard of Hearing People (see **Organizations That Offer Resources** in this section for contact information):

*Assistive Devices: Doorways to Independence* by Cindy Compton (video and book). Open-captioned.

*Communication Rules for Hard of Hearing People* by Sam Trychin, Ph.D. (video and manual). Open-captioned.

*Getting the Most Out of Your Hearing Aids* by C. Everett Koop, M.D. Open-captioned, 30 minutes.

*Hear's to the ADA*. Open-captioned, 23 minutes.

*I See What You Say* by Mary Kleeman. Hearing Visions, 1995, 54-minute video and 57-page manual (also available from the Alexander Graham Bell Association, which produced it). Closed captioned.

The following videotapes can be purchased from the League for the Hard of Hearing (see **Organizations That Offer Resources** in this section for address):

*Come Hear with Me*. Open-captioned, 15 minutes.

*I Only Hear You When I See Your Face*. Hope for Hearing Foundation. Captioned, 11 minutes.

*I See What You're Saying: a Practical Guide to Speechreading*. 2-tape set including handbooks. Open-captioned.

### Periodicals

*Hearing Loss* (bimonthly journal available with membership from SHHH—see **Organizations That Offer Resources** in this section for contact information).

*Hearing Health* (quarterly)  
P.O. Drawer V  
Ingleside, TX 78362  
361-776-7240 Voice/TTY  
[www.hearinghealthmag.com](http://www.hearinghealthmag.com)

### **Organizations That Offer Resources**

Alexander Graham Bell Association for the Deaf and Hard of Hearing  
3417 Volta Place NW  
Washington, DC 20007  
202-337-5220 Voice  
202-337-5221 TTY  
[www.agbell.org](http://www.agbell.org)

American Speech-Language-Hearing Association  
10801 Rockville Pike  
Rockville, MD 20852  
888-321-ASHA  
[www.asha.org](http://www.asha.org)

Association of Late-Deafened Adults  
1131 Lake Street, #204  
Oak Park, IL 60301  
708-358-0135 TTY  
877-348-7537  
[www.alda.org](http://www.alda.org)

Canadian Deafened Persons Association  
310 Elmgrove Road  
Ottawa, ON K1A 3L1  
613-729-6274 TTY/Voice  
613-729-5265 Fax

Canadian Hard of Hearing Association  
2435 Holly Lane, Suite 205  
Ottawa, ON K1V 7P2  
613-526-2692 TTY  
613-526-1584 Voice  
613-729-6274 Fax

League for the Hard of Hearing  
71 West 23rd Street  
New York, NY 10010-4162  
917-305-7700 Voice  
917-305-7999 TTY  
[www.lhh.org](http://www.lhh.org)

Self Help for Hard of Hearing People, Inc.  
7910 Woodmont Avenue, Suite 1200  
Bethesda, MD 20814  
301-657-2248 Voice  
301-657-2249 TTY  
[www.shhh.org](http://www.shhh.org)

### **United Methodist Resources**

National Committee on Ministries with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People  
Health and Welfare Ministries Unit  
General Board of Global Ministries  
The United Methodist Church  
475 Riverside Dr., Room 330  
New York, NY 10115  
212-870-3870

### **Assistive Listening Devices and Systems**

#### Manufacturers

Audex (infrared)  
710 Standard St.  
Longview, TX 75604  
903-295-8244  
800-237-0716  
[www.audex.com](http://www.audex.com)

Centrum Sound (CM-3 triangular conference microphone; also sells FM, infrared, and induction loops from other manufacturers)  
572 La Conner Dr.  
Sunnyvale, CA 94087  
408-736-6500  
<http://centrumsound.com>

Oval Window Audio (induction loop)  
33 Wildflower Court  
Nederland, CO 80466  
303-447-3607  
[www.ovalwindowaudio.com](http://www.ovalwindowaudio.com)

Phonic Ear (FM and infrared)  
3880 Cypress Drive  
Petulama, CA 95954  
707-769-1110  
800-227-0735  
[www.phonicear.com](http://www.phonicear.com)

Williams Sound (FM and infrared)  
10399 West 70th Street  
Eden Prairie, MN 55344  
612-943-2252  
800-328-6190  
[www.williamsound.com](http://www.williamsound.com)

### Distributors

The following distributors carry assistive listening devices and systems (as well as other assistive equipment such as TTYs) from various manufacturers. Request the current catalog.

HARC Mercantile Ltd.  
Hearing Aid Center of Kalamazoo  
P.O. Box 3055  
Kalamazoo, MI 49003  
800-445-9968 Voice/TTY  
[www.harcmercantile.com](http://www.harcmercantile.com)

Harris Communications, Inc.  
15159 Technology Drive  
Eden Prairie, MN 55344-7714  
800-825-6758 Voice  
800-825-9187 TTY  
[www.harriscomm.com](http://www.harriscomm.com)

Hear-More  
42 Executive Blvd.

Farmingdale, New York 11735  
631-752-0738  
800-881-4327 Voice/TTY  
[www.hearmore.com](http://www.hearmore.com)

HITEC  
8160 Madison Avenue  
Burr Ridge, IL 60521  
800-288-8303 Voice  
800-536-8890 TTY  
[www.hitec.com](http://www.hitec.com)

Potomac Technology  
One Church Street, Suite 101  
Rockville, MD 20850  
800-433-2838 Voice/TTY  
[www.potomactech.com](http://www.potomactech.com)

WCI  
2716 Ocean Park Blvd., Suite 1007  
Santa Monica, CA 90405  
800-233-9130 Voice/TTY  
[www.weitbrecht.com](http://www.weitbrecht.com)

## **DEAF-BLIND RESOURCES**

### **Organizations**

American Association of the Deaf-Blind  
814 Thayer Avenue  
Silver Spring, MD 20910  
301-588-6545 TTY

Helen Keller National Center for Deaf-Blind  
Youths and Adults  
111 Middle Neck Road  
Sands Point, NY 11050  
516-944-8900 Voice  
516-944-8637 TTY  
[www.helenkeller.org/national/index.htm](http://www.helenkeller.org/national/index.htm)

## Books

Kates, Linda and Schein, Jerome D. *A Complete Guide to Communication with Deaf-Blind Persons*. Silver Spring, MD: National Association of the Deaf, 1980. (Out of print).

Lieberman, Lauren J. and Cowart, Jim F. *Games for People with Sensory Impairments: Strategies for Including Individuals of All Ages*. Champaign, IL: Human Kinetics Publishers, 1998.

Sauerburger, Donna. *Independence without Sight or Sound: Suggestions for Practitioners Working with Deaf-Blind Adults*. New York: American Foundation for the Blind, 1993.

Smith, Theresa. *Guidelines: Practical Tips for Working and Socializing with Deaf-Blind People*. Burtonsville, MD, Sign Media, 1994.

## Article

Smith, Theresa. "Guidelines for Working/Playing with Deaf-Blind People." Available at the following website:  
[www.jsu.edu/depart/dss/links/body/deafblind.htm](http://www.jsu.edu/depart/dss/links/body/deafblind.htm).

## Videotapes

"Deaf-Blind Communication and Community: An Overview and Introduction." (2 tapes, 130 minutes total). Burtonsville, MD, Sign Media.

"Deaf-Blind Communication and Community: Getting Involved—A Conversation" (90 minutes). Burtonsville, MD, Sign Media.

# Glossary

**ADA** (See Americans with Disabilities Act.)

**AMD** (See macular degeneration.)

**American Sign Language (ASL)** The visual, manual language of the Deaf culture. It is a true language with its own grammar, syntax, and lexicon (vocabulary).

**Americans with Disabilities Act (ADA)** A federal law, passed in 1990, that makes it illegal to discriminate against people with disabilities in the public sphere (restaurants, hotels, state and local governments, etc.) and on the job (hiring and firing practices, etc.). While this is a major advancement in the protection of civil rights for people with disabilities, churches are exempt from the law's provisions.

**ASL** (See American Sign Language.)

**assistive listening device** (See assistive listening system.)

**assistive listening system** Transmitting/receiving equipment that transmits sound from the microphone directly to the hard of hearing listener, minimizing the negative effects of distance, noise, and reverberation (echo) on clarity. Assistive listening systems include FM, induction loop, and infrared systems, all of which are wireless. Assistive listening systems are used for large areas; assistive listening devices (which can be wireless or hard-wired) are for personal use.

**Association of Late-Deafened Adults (ALDA)** A Chicago-based organization that publishes a newsletter, sponsors an annual conference, and helps build a network of people who have become deaf after acquiring spoken language.

New chapters are being formed around the country.

**audiological deafness** Deafness that is physiological in origin. This term is used to refer to a medical condition as opposed to a cultural identification.

**audiologist** A professional (though not a doctor) who tests hearing and can diagnose the degree of hearing loss. An audiologist can also recommend and fit a person with a hearing aid appropriate to his or her specific hearing loss.

**auditory brainstem implant (ABI)** This alternative to a cochlear implant was developed for people who no longer have a functioning auditory nerve.

**bicultural** Knowledgeable about two different cultures and comfortable with moving back and forth between them. For our purposes, bicultural usually means living comfortably in both the deaf and the hearing cultures.

**bilingual** Fluent in two different languages and comfortable with switching from one language to the other. For our purposes, bilingual usually means fluent in both American Sign Language and English.

**bluffing** A technique that deaf, late-deafened, and hard of hearing people use when they don't understand what is said, but they don't want to interrupt or ask people to repeat themselves. Usually they will nod their heads in agreement with something that they did not understand. Hearing people bluff as well when they don't understand something a deaf person has signed to them.

**CART** Computer-aided realtime translation, in which a court reporter uses a special stenotype machine and a computer to display, on a computer monitor or screen, a nearly verbatim rendition of words as they are spoken. Used by late-deafened and some oral deaf and hard of hearing people.

**closed captions** Explanations or dialogue similar to subtitles printed at the bottom of the screen in foreign films. If a TV program or video is closed-captioned, a device called a "decoder" (now included in TVs larger than 13") can access the captions. The difference between closed and open captions is that closed captions are only displayed when accessed via a decoder, whereas open captions are visible at all times.

**cochlea** A cavity in the inner ear containing hair cells that respond to sound waves by producing electrical signals which transmit the sounds to auditory nerve fibers.

**cochlear implant (CI)** A device involving an externally worn speech processor and an array of electrodes implanted into the cochlea of the ear to stimulate the auditory nerve; used for hearing losses that are too severe to benefit from a hearing aid.

**CODAs** Children of Deaf adults.

**Code of Ethics** A list of rules that sign language interpreters promise to obey when they become certified by the Registry of Interpreters for the Deaf.

**code switch** To move from communicating in one language to communicating in another. For our purposes, code switching usually refers to switching between American Sign Language and a form of Signed English.

**communication mode** A way of communicat-

ing that is not a language in and of itself. For example, a signed version of English is not a language but a communication mode of English. Speechreading is a communication mode through which English is received by the eyes rather than the ears.

**computer-assisted notetaking** A relatively new technology that permits notes to be displayed as they are taken so that hard of hearing, late-deafened, and deaf people who are fluent in a written language can follow the course of a discussion, meeting, or lecture. The technology employs a computer hooked to either a monitor or a liquid crystal display (LCD) that sits on top of an overhead projector. The operator (a typist called a "computer-assisted notetaker") types notes into the computer, and the notes are then displayed on the monitor, or via an overhead projector if the group is too large to sit around a monitor.

**conference microphone** A microphone setup designed to pick up the voices of speakers around a meeting table. One type is a box with a multidirectional microphone that sits at the center of a table; this type is more effective in picking up those seated nearby.

**contact language** A language that results when two cultures come into contact. An example is Pidgin Signed English.

**C-Print** A computer-aided speech-to-print transcription system developed by the National Technical Institute of the Deaf (NTID), in which a typist (C-Print captionist) uses special abbreviation software to type a condensed version of the spoken words on a laptop computer, and the information is simultaneously displayed on a second laptop computer or (particularly for display to several viewers) a TV or other screen. Currently used primarily in the classroom.



Typewell is a similar transcription system that was subsequently developed elsewhere.

**cued speech** A communication method in which eight hand configurations and four hand positions (the side of the face, the throat, the chin, and a corner of the mouth) are used simultaneously with speechreading. These supplemental "cues" provide phonetic information that is often not discernible from speechreading alone.

**culturally deaf** Identifying with the values and worldview of the Deaf culture, whose preferred language is American Sign Language. Culturally deaf people associate primarily with the deaf community. "Culturally deaf" is sometimes abbreviated as Deaf with a capital D.

**culturally hearing** Identifying with the values and worldview of hearing people, whose preferred language is English or the oral language of their family. Culturally hearing people may be late-deafened or hard of hearing, but they associate primarily with hearing people.

**deaf** A general term meaning either (1) audiologically incapable of understanding speech through the ear or (2) (often with a capital D) culturally deaf.

**Deaf** (spelled with a capital D) A specific term meaning culturally deaf.

**deaf-blind** Refers to people who have significant, but not necessarily total, loss of both vision and hearing (dual sensory loss). Deaf-blind people may be culturally deaf, oral deaf, late-deafened, or hard of hearing, and their mode of communication varies accordingly. The dual sensory loss may be due to illness, injury, age-related losses, or genetically caused conditions like Usher's Syndrome.

**Deaf community** A community composed of

those who are culturally deaf, as well as people with a wide variety of hearing loss and communication modes who share experiences, needs, and goals with them. Structurally, the Deaf community can be local or national, and in reality it is a social community as well as a political one.

**Deaf culture** A set of values, modes of behavior, and folklore common to those who were born deaf to deaf parents. The Deaf culture has American Sign Language as its linguistic base. Children with hearing loss who were not born deaf to deaf parents may become members of the Deaf culture when they attend residential schools for the Deaf.

**decoder** A device that can be attached to a television to pick up closed captions. (Also see "Television Decoder Circuitry Act.")

**electromagnetic field** An invisible field that can be created by induction loop wire encircling a room or part of a room. The induction loop assistive listening system operates by creating an electromagnetic field around the loop wire, which is connected to an amplifier. The sound is picked up within this field and transmitted directly to a person's hearing aid if there is a telecoil in the hearing aid. (A hearing aid equipped with a telecoil has a T-switch on the outside.) Those who lack telecoils need to use an induction loop receiver.

**English-based sign system** A generic term that covers a variety of sign systems and manual codes of English. It can be used in conjunction with spoken English or by itself. (See also Linguistics of Visual English, Pidgin Signed English, Seeing Essential English, Signing Exact English.)

**fingerspelling** Communication by use of a manual alphabet. Each letter has a different

handshape, and the hand successively displays the shapes needed to spell out the desired words. Fingerspelling is used primarily for spelling names and other terms for which no sign is available. It can also be used to spell words into the palm of a deaf-blind person.

**FM system** An assistive listening system that uses a transmitter similar to a small radio station and a receiver resembling a pager-sized FM radio. The sound is transmitted on designated radio frequencies and the signal is received through earphones plugged into the receiver. Instead of earphones, people with telecoil-equipped hearing aids use a neckloop plugged into the receiver and turn on their T-switch.

**graphic notetaking** A visual method of taking notes, usually done with colored markers on either newsprint or large butcher paper taped to a wall or blackboard. It is a communication tool used in meetings that allows Deaf, late-deafened, and hard of hearing people to follow the conversation. (Culturally deaf people who are not fluent in English may not prefer this method.)

**hard of hearing** Refers to people who have a hearing loss but are able to understand speech through the ear with the help of hearing aids and/or assistive listening equipment. Most hard of hearing people are culturally hearing and use English (or another native spoken language) as their primary language. Some were born hard of hearing, but most develop their hearing loss later in life. Some have a profound hearing loss and are "deaf" by audiological standards, but because they are culturally hearing, they do not associate with other deaf people, do not use sign language, and identify more with the hearing population. (The term "late-deafened" came into use to describe such audilogically deaf/culturally hearing people, but many still refer to themselves as "hard of hearing.")

**hard-wired** Refers to a sound-transmission technology that requires wires to run from the transmitter to the receiver. It is appropriate for one-on-one visitation or counseling but is too awkward for large rooms containing many people.

**hearing** An adjective that refers to people who not only have "normal" hearing but also approach life from an oral/aural perspective. This term is used to describe individuals (hearing people), churches (hearing churches), worship (hearing worship), and culture (hearing culture).

**hearing impaired** A generic term that refers to all people with any degree of hearing loss. Many Deaf people do not appreciate this term because they believe it compares them unfavorably with the majority hearing culture and implies that deafness is a limiting factor in their lives. More and more, this term is used to represent only those who are late-deafened or hard of hearing. The terms that are considered most appropriate today are Deaf, late-deafened, and hard of hearing.

**Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)** A campus in Long Island, New York, with residential facilities and a training building, which provides vocational rehabilitation and training in independent living for deaf-blind people. The center also has 10 regional offices, 40 affiliates, and an older adult program.

**infrared system** An assistive listening system that uses infrared light to transmit sound. Instead of wearing headphones or headsets, people with telecoil-equipped hearing aids plug a neckloop into the receiver. Headphones and headsets may lack the jacks needed for this purpose, so receivers with jacks must be provided. Small infrared systems for use with home TVs are available.

**induction loop system** An assistive listening system that transmits sound via an electromagnetic field created by current running through loop wire. The sound is transmitted from a microphone through an amplifier into the electromagnetic field. Any person in the room wearing a hearing aid with a built-in telecoil can receive the transmitted signal by setting a T-switch on the hearing aid. For those whose hearing aids are not equipped with a telecoil, receivers must be purchased. The system can transmit through walls, floors, and ceilings, so two loop systems cannot operate simultaneously in adjoining rooms.

**interpreter** A person who is bilingual and translates one language to another. For our purposes, an interpreter is a person who listens to spoken English and transmits it as sign language or vice versa. Interpreters may work between two languages (such as English and ASL) or between two different communication modes of the same language (such as spoken English and a manual code of English). An interpreter does not provide a literal translation but conveys the "spirit" of what is being expressed.

**language** A spoken or signed system of communication that has its own grammar, syntax, lexicon, and semantics. English is a language and American Sign Language is a language, whereas forms of Signed English are communication modes based on the English language.

**late-deafened** Refers to people who became deaf postlingually (after learning to speak) and were raised in the hearing community; most do not learn sign language, and they usually experience a tremendous sense of loss when they lose their hearing.

**LCD** (See liquid crystal display.)

**Linguistics of Visual English (LOVE)** A manual code created to reproduce the English language.

**lipsynch** To form words with the mouth without creating any sound. Sign language interpreters will use this technique simultaneously with signing in some form of English for those who depend on speechreading as well as signs for comprehension. Oral interpreters use this technique exclusively. They will sit in proximity to the people who are speechreading and lip-synch for them everything the speaker is saying.

**liquid crystal display (LCD)** A digital device that consists of two sheets of glass separated by sealed-in liquid crystal material. A voltage applied to the material darkens the liquid enough to form letters and numbers in pre-arranged patterns.

**LOVE** (See Linguistics of Visual English.)

**macular degeneration** (also referred to as "age-related macular degeneration," or AMD) The leading cause of blindness in older people. AMD involves damage to the macula, a small area at the back of the eye that is responsible for central vision. Activities that require sharp vision, such as reading, driving, and threading a needle, become impossible.

**mainstreaming** The process of integrating a few deaf people with a majority of hearing people. Also, the process of educating students with disabilities in regular public schools rather than in separate classrooms or special schools.

**manual codes of English** Signing systems that have been developed in order to transmit the English language manually. The most common of these manually coded English systems are Seeing Essential English (SEE I), Signing Exact English (SEE II), and Linguistics of Visual English (LOVE).

**meningitis** Inflammation of the membrane covering the brain and spinal cord, usually caused by certain viruses and bacteria. Bacterial meningitis can be fatal if not promptly treated and can cause permanent brain damage, resulting in deafness, blindness, mental retardation, seizures, and/or various other medical problems.

**multicultural** Knowledgeable of three or more cultures and able to move among the cultures and recognize the behaviors required by each. For our purposes, multicultural usually means knowledgeable of the Deaf and hearing cultures, as well as of a racial minority culture, such as black, Latino, or Asian.

**multilingual** Knowledgeable in three or more languages. For our purposes, multilingual usually means able to communicate in both American Sign Language and English as well as in another language such as Black Sign Language, Hispanic Sign Language, Spanish, Korean Sign Language, or Korean.

**National Association of the Deaf (NAD)** A national organization established in 1880 and located in Silver Spring, Maryland, with 51 state and District of Columbia affiliates. Holds a biennial convention, issues publications, certifies sign language interpreters, promotes activities for Deaf youth, has a Law Center, and represents the interests of the culturally deaf community.

**neurofibromatosis type 2 (NF2)** A dominantly inherited disorder affecting approximately 1 in 50,000 people. It causes tumors to develop on nerves, particularly damaging the auditory nerves and resulting in deafness. Because the auditory nerve becomes nonfunctional, people with NF2 cannot use cochlear implants, but they may be candidates for the auditory brain-stem implant.

**neckloop** A small induction loop that is worn around the neck and plugged into an FM or infrared assistive listening system receiver. The neckloop converts the receiver's transmission to an electromagnetic signal, which is picked up by a hearing aid telecoil.

**oral deaf** Refers to people who were born deaf or became deaf prelingually but were taught to speak and speechread; they do not use sign language for communication.

**oral interpreter** An interpreter who does not use any sign language but sits in proximity to those who are speechreading and lipsynchs what the speaker is saying (making word substitutions as necessary for easier speechreading). The deaf or hard of hearing person then speechreads the oral interpreter rather than the speaker.

**Pidgin Signed English (PSE)** A communication mode that utilizes many components of American Sign Language but relies on English grammar structure. It can be communicated with or without spoken English. The term PSE is being replaced in linguistic circles by "contact signing," because it is not a true pidgin language and instead follows the rules of other contact languages.

**Pocketalker**™ A hard-wired personal assistive listening device.

**postlingual** Occurring after the acquisition of spoken language.

**prelingual** Occurring before the acquisition of spoken language.

**presbycusis** Hearing loss resulting from the aging process. In many cases it not only decreases the volume of sounds heard but also affects the ability to distinguish consonants, because the loss is usually greater in the higher frequencies.

**PSE** (See Pidgin Signed English.)

**Registry of Interpreters for the Deaf (RID)** An organization that decides what rules will be included in the Code of Ethics for interpreters, and designs the tests that will be given and the evaluation procedures used for certifying interpreters. RID keeps lists of certified interpreters and has chapters all over the country. It can provide names of certified interpreters in your local area. (The National Association of the Deaf and states also certify interpreters.)

**relay service** A free nationwide telephone service mandated by the Americans with Disabilities Act, which enables deaf and late-deafened people to communicate by telephone with hearing people who do not have access to a TTY (see TTY). A communication assistant serves as an intermediary during the conversation, typing to the TTY user what the hearing person says and voicing to the hearing person what the TTY user types. (A technique called "voice carryover," or "VCO," enables TTY users who can speak to use their own voice,

and this method is especially suitable for late-deafened people.)

**residential schools** State-administered schools for Deaf children that are cherished by the Deaf culture as places where language, culture, values, and folklore are learned and shared. Most of the students live in dormitories and create a "family" that they remain close to for the rest of their lives.

**residual hearing** The hearing that remains after a hearing loss.

**retina** The light-sensitive inner lining of the eye, which receives images from the lens and transmits them to the optic nerve.

**retinitis pigmentosa** An inherited progressive degeneration of the retina that first affects night vision and peripheral (side vision), leading to "tunnel vision" and ultimately blindness. Usher Syndrome is an inherited combination of retinitis pigmentosa and hearing loss.

**reverse interpreter** A reverse interpreter, or voice interpreter, watches what a Deaf person is signing and voices it for the hearing people in the audience.

**RID** (See Registry of Interpreters for the Deaf.)

**rubella** Also known as German measles; a viral infection (usually mild in adults) that can cause deafness, blindness, and other disabilities in an unborn child when acquired by a woman during the first three months of pregnancy. Many babies were affected by a rubella epidemic in the 1960s, but the disease has become uncommon since the development of a vaccine to prevent it.

**secondary audio programming (SAP)** This is an alternative audio signal that is only heard when the SAP channel is activated. Among other purposes, it can be used to provide a description of a program's visual activity for those who are visually impaired. Listeners can access SAP through a TV or VCR equipped to receive SAP signals or with a special SAP decoder. (Most stereo TVs and VCRs made in 1995 or later can receive SAP.)

**SEE I** (See Seeing Essential English.)

**SEE II** (See Signing Exact English.)

**Seeing Essential English (SEE I)** A manual code created to reproduce the English language.

**Self Help for Hard of Hearing People (SHHH)** A national organization headquartered in Bethesda, Maryland, with chapters around the country, which sponsors an annual conference, produces a bimonthly journal, and publishes a catalog of books, articles, and videos about hearing loss.

**Signing Exact English (SEE II)** A manual code created to reproduce the English language.

**simultaneous communication** Signing and speaking at the same time. The term can be misleading because, while two communication modes exist simultaneously, two languages generally do not. When someone attempts to speak and sign simultaneously, usually the English delivery is fluent but the sign communication suffers.

**speechreading** The technical term for what most people know as "lipreading." Speechreading is difficult, because only about 30 percent of spoken English is produced visibly on the lips; the remainder is formed inside the mouth and out of sight.

**tactile communication** Signing or finger-spelling into the hands; used for communicating with some deaf-blind people.

**TDD** Abbreviation for "Telecommunication Device for the Deaf." TDD is a relatively recent generic term that includes all the various models of machines that convert telephone communication to and from a visible print format. The term was invented by hearing people and is therefore most acceptable to those who are late-deafened or hard of hearing. Most culturally deaf people still use the traditional term "TTY" (teletype machine) to refer to any kind of telecommunication device.

**telecoil** A tiny device built into certain hearing aids that allows the wearer to hear better on the telephone and to pick up signals from an induction loop assistive listening system (without the need for a receiver) or from a neckloop plugged into an FM or infrared receiver. Anyone buying a hearing aid should make sure it comes equipped with a telecoil (also called a T-switch).

**telephone relay service** (See relay service.)

**Television Decoder Circuitry Act** A federal law effective as of July 1, 1993, that requires all television manufacturing companies to include, in televisions 13 inches or larger, a chip that provides access to closed captioning.

**transliteration** Signing in English word order instead of in American Sign Language. Late-deafened adults who sign generally use transliteration and require this form of interpreting.

**T-switch** (See telecoil.)

**TTY** The term preferred by culturally deaf people for the machine (originally a teletype machine) with which they communicate over the telephone. The message is sent through the phone wire and converted into print so that the

Deaf person can read what is said and type a message back. Because newer TTYs no longer rely on Teletype technology, the term "TDD" (Telecommunication Device for the Deaf) was invented, but the culturally deaf community still prefers to use the term TTY for all forms of telecommunication devices.

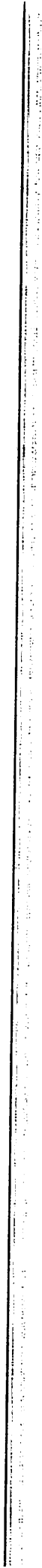
**Typewell** (See C-Print.)

**Usher Syndrome** The most common cause of deaf-blindness among younger people. It is transmitted recessively—both parents need to be carri-

ers—and involves varying degrees of hearing loss accompanied by retinitis pigmentosa, which involves progressive destruction of the retina of the eyes from the periphery to the center.

**voice carryover** (VCO) TTY (See relay service.)

**wireless** A technology that permits transmission of sound to a receiver without use of wires. The most common wireless assistive listening systems are FM (which uses radio waves), induction loop (which uses an electromagnetic field), and infrared (which uses light waves).





# Accessibility Audit for Ministry

## **ACCESS FOR DEAF, HARD OF HEARING, LATE-DEAFENED, AND DEAF-BLIND PEOPLE<sup>1</sup>**

This audit form will help you determine how to make your church accessible for Deaf, late-deafened, hard of hearing, and deaf-blind people in your community and church. (Note that most hard of hearing people hear better if they see what is being spoken, in addition to hearing it with the help of hearing aids and/or assistive listening devices; people who are deaf or late-deafened **MUST** have information communicated visually.)

### **Outreach to the Culturally Deaf Community**

- \_\_\_ Is your church willing to recruit and support an ASL interpreter with both financial and spiritual resources?
- \_\_\_ Is your church prepared to become a multi-cultural congregation committed to full involvement of culturally deaf members?
- \_\_\_ Is your church willing to commit itself to learning about Deaf culture and ASL in order to provide a truly welcoming atmosphere?
- \_\_\_ Is your church willing to reflect on and repent for the experiences of oppression and exclusion culturally deaf people have had in relation to churches and the larger society?
- \_\_\_ Is your church willing to become an advocate for the improvement of the lives of Deaf children and adults?

- \_\_\_ Is your church able to provide meaningful involvement in worship and church life for families with both Deaf and hearing members of all ages?

### **Sound Adaptations for Hard of Hearing People**

Which of the following sound adaptations has your church made to encourage participation by hard of hearing people?

In the sanctuary:

- \_\_\_ Amplification for the whole congregation (this does NOT substitute for an assistive listening system for hard of hearing people and those using cochlear implants).
- \_\_\_ Microphone positioned away from speaker's lips, to accommodate people who speechread.
- \_\_\_ Lighting in front of liturgists, preachers, and choir members to facilitate speechreading.
- \_\_\_ Lavalier (lapel) microphone worn by liturgists and preachers not using a stationary microphone.
- \_\_\_ Wireless microphone for use in the nave for sharing joys and concerns or additional announcements.
- \_\_\_ Strategically placed microphones so that people using assistive listening devices can hear organ/piano, soloists, and choir.
- \_\_\_ Assistive listening system (FM, infrared, or induction loop).

<sup>1</sup> This document is derived from a model audit form prepared by Holly Elliott and Dr. Laurel Glass for use in the Oregon-Idaho Annual Conference of The United Methodist Church and focuses on the needs of hard of hearing and late-deafened people, most of whom do not understand sign language.

- \_\_\_ Neckloops and receivers with jacks for the assistive listening system (needed by people with cochlear implants or hearing aids with T-switches).
- \_\_\_ Person assigned to ensure that receiver batteries are charged (or replaced as needed) each week.
- \_\_\_ Assistive listening receivers set out on table or close to sanctuary, enabling easy access by users.
- \_\_\_ An attendant on hand to assist in selection and operation of proper unit.
- \_\_\_ Notices placed at entry points announcing the availability of assistive listening devices and where to find them.
- \_\_\_ Announcement of assistive listening system and visual communication access in church's yellow page, website, newspaper advertisements, and other publicity.
- \_\_\_ When remodeling or building new sanctuary, architect requested to research and utilize best acoustical design.

#### In meeting rooms:

- \_\_\_ Meetings held in rooms with good acoustics (carpets, drapes).
- \_\_\_ Good lighting on speaker's face.
- \_\_\_ Amplification used most of the time.
- \_\_\_ Microphone positioned away from speaker's mouth.
- \_\_\_ Microphone used by all speakers, including those in audience during feedback or discussion time.
- \_\_\_ All presentations done from the front (to facilitate hearing and speechreading).
- \_\_\_ Comments and questions from audience repeated by speaker (if microphone is not available to the audience).
- \_\_\_ Semicircular seating arrangement used for discussion to facilitate speechreading.

- \_\_\_ Assistive listening system available.
- \_\_\_ Neckloops and receivers with jacks available for assistive listening system.
- \_\_\_ Videos with closed captions selected and captions displayed.
- \_\_\_ TV sets equipped with closed-captioned circuitry, TV remote available, and instructions or attendant on hand for displaying the captions.

#### Visual Adaptations

In which of the following ways does your church supplement sound with sight for late-deafened people? (These methods also benefit hard of hearing people.)

#### During worship:

- \_\_\_ Copies of sermon and other presentations available in advance.
- \_\_\_ Overhead projection provided to large screen in sanctuary.
- \_\_\_ Computer-assisted notetaking or similar system shown on TV or projected onto large screen.

Are the following visible to all worshipers? (Note that most hymnals and pew Bibles are in small print.)

- \_\_\_ Words of hymns
- \_\_\_ Words of anthem or solo
- \_\_\_ Litanies, prayers, Scripture readings
- \_\_\_ Words of the liturgy
- \_\_\_ Sermon
- \_\_\_ Children's moments
- \_\_\_ Congregational joys and concerns
- \_\_\_ Announcements

#### During meetings:

- \_\_\_ Written agenda, even for "small" meetings

- \_\_\_ Graphic notetaking throughout meetings, even small ones
- \_\_\_ Overhead projection, especially of action proposals
- \_\_\_ Computer-assisted notetaking visible to all
- \_\_\_ Use of captioned videos

### **Helps for Deaf-Blind People**

Which of the following has your church done for deaf-blind people (see Part Three, page 60 for more information)?

- \_\_\_ Inquired within the community for the purpose of identifying those who are living with deaf-blind condition.
- \_\_\_ Taken steps to invite deaf-blind people to participate in your church's life and work.
- \_\_\_ Interviewed the deaf-blind people to learn their specific needs and gifts. (Note: If a deaf-blind person has residual hearing and uses a hearing aid or a cochlear implant, follow the suggestions above for sound amplification and assistive listening systems.)

- \_\_\_ Provided a tactile interpreter (one for each deaf-blind person), if such service is needed.
- \_\_\_ Provided a trained guide to be available as needed.
- \_\_\_ Provided transportation as needed.
- \_\_\_ Made a large-print bulletin and hymnal available for each deaf-blind person with residual eyesight.
- \_\_\_ Provided handicap-accessible restrooms (very useful for deaf-blind people).

### **Telephones and One-on-One Communication**

Does your church provide the following communication access for the telephone and for interactions with staff?

- \_\_\_ At least one telephone with volume control for hard of hearing people.
- \_\_\_ A TTY (telecommunication device for the deaf, also known as a TDD).
- \_\_\_ A personal assistive listening device (e.g., Pocketalker™) for counseling sessions and home/hospital visits with hard of hearing people.

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